University of Alberta

A Pilot Study of Quality of Life of Young Adults with Asperger Syndrome

by

Marieke Coussens

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the

requirements for the Master of Science

Department of Occupational Therapy

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Feb. 25, 2003

There is, it seems to us,
At best, only a limited value
In the knowledge derived from experience.
The knowledge imposes a pattern and falsifies,
For the pattern is new in every moment
And every moment is a new and shocking
Valuation of all we have been…
The only wisdom we can hope to acquire
Is the wisdom of humility: humility is endless.

T. S. Eliot
Four Quartets

Abstract

Factors influencing the quality of life for persons with Asperger Syndrome (AS), a disorder characterized by impaired social interactions and restricted interests, are poorly understood. Such information is needed for effective programming. Men, ages 18 to 21 and living in the community, completed the World Health Organization Quality Of Life measure, the Perceived Support Network Inventory, and a semi-structured interview. The 12 men with AS reported a significantly lower quality of life on the social and physical domains than did the 13 men in the control group. Perceived social support, educational experiences, leisure activities, and number of friends were remarkably similar between groups. Those with AS had less positive experiences regarding employment, income and dating. The results indicate that AS affects aspects of quality of life beyond the obvious social impact and as such interventions need to consider all aspects of the person within a holistic model of practice.

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It was a long and winding road but the destination was sweet. In the spirit of feeling gratefulness for having reached this point of fulfillment, I would like to acknowledge those without whom the journey would have been much less fun.

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INTRODUCTION

Problem Statement

Asperger Syndrome is a developmental disorder that is characterized by difficulties in social relationships, verbal and non-verbal communication as well as restrictive and repetitive patterns of behaviours, interests and activities. These difficulties cause significant problems in social, occupational or other important areas of functioning (American Psychiatric Association, 2000).

In recent years, both professionals and the general public have become more aware of Asperger Syndrome although little is known about its impact across the life span. With prevalence rates of 2 per 10,000 people (Fombonne, 2001), researchers and practitioners are concerned about the outcomes for adults in the areas of education, employment, independence, social relationships, behaviour and mental health (Ghaziuddin, Ghaziuddin & Weidmer-Mikhail, 1998; Goode & Howlin, 1998; Howlin, 2000, Howlin & Mawhood, 1999). Information about outcome comes from a variety of sources including autobiographical accounts. Positive outcome has traditionally been defined as the achievement of independence and a normal social life (Larsen & Mouridsen, 1997; Lotter, 1978). The conventional framework for outcome assessment within the autism and Asperger Syndrome literature has identified linguistic and cognitive variables as the best predictors of a positive outcome. However, Dalrymple and Ruble (1996) argue that these cognitive and linguistic variables do not change much over time and, therefore, are of limited use to parents and educators. They argue that variables that are susceptible to mediation, such as quality of life, should be the focus of future outcome research. According to Dalrymple and Ruble, 'positive outcome' is best conceptualized in terms of the interaction of the environment and the person. The environment supplies protective factors such as supports and adaptations that serve to counterbalance risk factors such as environmental and personal challenges. The relationships between protective and risk factors provide the link between assessment and intervention. Dalrymple and Ruble's more recent characterization of outcome is meaningful because it addresses the impact of Asperger Syndrome on a person's quality of life and it includes the effects of environmental variables on the outcome of individuals that could be altered by intervention.

According to Tantam (1991), the effects of Asperger Syndrome are greatest in adolescence and young adulthood. This may be related to the fact that successful relationships are the key to almost every achievement in these age groups. This transition period encompasses the launching phase into adulthood and entails completing school, finding satisfying work, developing a social network, contributing to the maintenance and support of a household, and participating as a citizen in a community (Collins, Davis & Vander Stoep, 2000). Not surprisingly, it is during this transition period that individuals with Asperger Syndrome frequently suffer from mental health problems such as depression and anxiety (Bryson, Kim, Streiner, Szatmari & Wilson, 2000; Stoddart, 1999). The quality of life for persons with Asperger Syndrome during this transition period has not yet received systematic study (Dalrymple & Ruble). Social support has also not been examined even though perceived social support is positively correlated with well being among adults and adolescents (Cause, Gonzales, Hiraga, Liu & Mason, 1994).

This study explored the quality of life of individuals with Asperger Syndrome, their perceived social support and their self-perception on general outcomes in these domains of: 1) independence, 2) friends and dating and 3) leisure pursuits.

Characteristics associated with variations in quality of life may provide insight into areas of the client's life that could be enhanced by intervention thus allowing their successful participation in meaningful and age appropriate occupations.

Objectives of the Study:

The primary objectives of this study were:

- to compare the quality of life of young male adults diagnosed with Asperger Syndrome to young male adults without Asperger Syndrome,
- to examine differences in the perceived support network of young male adults with Asperger Syndrome and those without Asperger Syndrome, and
- to describe trends in three areas related to quality of life (level of independence, social relationships such as friends and dating, and leisure activities) for persons with and without Asperger Syndrome.

Hypotheses

It was hypothesized that:

1. The quality of life scores for young adults with Asperger Syndrome on the World Health Organization of Quality Of Life –Brief version (WHOQOL-BREF) would be significantly lower than for those without Asperger Syndrome.

It was anticipated that post-hoc analyses would indicate that the differences would lie primarily in the social and the psychological domain.

2. The total scores on the Perceived Support Network Inventory (PSNI) for the young adults with Asperger Syndrome would be significantly different than those

without Asperger Syndrome.

If Hypothesis 2 were supported, the sub-scale scores on the PSNI would be further investigated.

It was also expected that there would be a positive relationship between total scores on the PSNI and the overall quality of life score on the WHOQOL-BREF for both groups of young adults.

No hypotheses were generated related to the third objective of this study that dealt with describing three quality of life domains based on the WHOQOL model in more detail for young adults with and without Asperger Syndrome. The purpose was to identify trends in (1) level of independence, which included education, employment, living arrangements, and mobility; (2) social relationships, more specifically dating relationships and friends; and (3) one aspect of the environment, leisure pursuits.

CHAPTER ONE

SELECTED LITERATURE REVIEW

To lay the necessary foundation for this study the relevant literature is presented. First, literature related to quality of life is reviewed. Second, a description of Asperger Syndrome and the impact of the disorder on quality of life is discussed. Third, the relationship between quality of life and social support is addressed.

Quality of Life

Defining Quality of Life

In the 1960s and 1970s there was growing consumer dissatisfaction with health care as medical treatments focused almost exclusively on treatment needs and tended to overlook the basic human needs of its patients such as well-being, autonomy and sense of belonging (Carr, Gibson & Robinson, 2001). According to Carr and colleagues, the way society currently thinks about health and health care is changing. One factor driving this change is the recognition of the importance of the social consequences of diseases and disabilities for the client's quality of life. This is specifically relevant for those clients who live without expectations of being cured and have conditions that are likely to have an impact on their psychological, physical and social well being. Hence, quality of life is now a more valued assessment in many areas of health care. As indicated by Herrman, Orley and Saxena (1998), the current trend of measuring quality of life reflects a more consumer-oriented approach to health care in which the client's own opinion of what is happening to them is viewed as important. For these reasons, the effectiveness of interventions as well as the quality of health care is often evaluated by its impact on clients' quality of life (Brown, Nagler & Renwick, 1996). However, Bodgan and Taylor (1990) argued that the use of quality of life as an outcome criterion for services is problematic, as no single definition of "quality of life" exists for people with or without disabilities. A lack of definitional consensus complicates efforts to operationalize quality of life as an outcome criterion (McDowell & Newell, 1996; Rogerson, 1995). Despite this lack of definitional consensus, Buxton, Davey, Fitzpatrick & Jones (1998) argue that quality of life has been adopted for use as an outcome measure because traditionally defined outcomes need to be complemented by measures focusing on the individual's concerns.

Definitions of quality of life range from those with a holistic emphasis on the social, psychological and physical well being of clients to those that describe the impact of a person's health on his or her ability to lead a fulfilling life (Carr and Higginson, 2001a). Just as there are many diverse definitions of quality of life, so too there are many models available in the literature. These models resulted in differing approaches to assessment and intervention depending upon their key concepts. In choosing a conceptual model to guide this study, it was important to include a model that considered the health of the individual and the multiple determinants of quality of life. For this study the perspective of the World Health Organization's working group on quality of life (WHOQOL) was used.

In 1991, the Division of Mental Health of the WHO initiated the World Health Organization Quality of Life (WHOQOL) project. The aim of the project was to develop an internationally applicable and cross-culturally comparable quality of life assessment (Melbourne WHOQOL Field Study & Centre, 2002). Since no widely accepted definition of quality of life was available, the WHOQOL Group attempted to clarify and define the concept. The group adopted a unique approach involving collaboration with 15 centres around the world and developed its conceptual framework in several stages (WHOQOL Group, 1994). The culturally diverse centres were involved in clarifying the concept of "quality of life" and in the operationalization of its domains. Healthy people, as well as health professionals in a variety of cultures drafted the important aspects of quality of life on the basis of statements made by patients with a wide range of diseases.

The WHOQOL Group defined quality of life as an "individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and relationships to salient features of his or her environment" (WHOQOL Group, 1998a, p. 551). According to Herrman and colleagues (1998), the emphases within this definition are on the subjective nature of quality of life and on the need to explore all parts of life considered as having a significant impact on quality of life. Hence, assessing quality of life is not expected to provide a means of measuring symptoms, disease, or conditions, but, rather, to determine the effects of disease and health interventions on quality of life (WHO, 1996). As such, the WHOQOL Group has argued that quality of life cannot be simply equated with the terms "health status," "lifestyle," "life satisfaction," "mental state" or "well-being." Rather, quality of life is a multidimensional concept incorporating the individual's perception of their mental state, well being, life satisfaction and other aspects of life such as health status.

Quality of Life and Health

Health is a term closely related to quality of life and from which definitions of quality of life have borrowed (Brown et al., 1996). Definitions of health have shifted from a medical model with a focus on the absence of illness, to a perception of health as a state of complete physical, mental, and social well-being (WHO, 1948) with a greater emphasis on the multiple determinants of health (Raeburn & Rootman, 1994). According to Brown and colleagues this shift in the definition of health has broadened the interventions used in rehabilitation medicine to include maintaining or enhancing the quality of life of individuals. They argued that quality of life is usually thought of as a broader concept than health, with health subsumed under quality of life. However, they also suggest that the relationship between the two concepts is considerably more complex. Health is often cited as "one of the most important determinants of overall quality of life" (McDowell & Newell, 1987, p. 205) but quality of life is also thought to be a determinant of overall health. Furthermore, the concept of health relates to the individuals' ability to achieve their potential and to respond positively to the challenges of their environment. As a result, health can be interpreted as an essential dimension of one's quality of life (Brown et al.). Consequently, any consideration of quality of life must also consider a client's health.

A Conceptual Model of Quality of Life

The WHOQOL used their definition of quality of life as a guiding framework for understanding the concept. According to Atkinson and Zibin (1996), most health theorists agree that depending on its use, a well rounded quality of life conceptual model and an assessment tool designed to evaluate quality of life, should include the following domains: health, self-esteem, well being, community, productivity, social and love relationships, and leisure (Atkinson & Zibin). Less frequently mentioned domains are family, living situations, finances, psychiatric symptoms and religion. The WHOQOL included all these important domains in their conceptual framework and was therefore chosen as the guiding framework of this study.

The WHOQOL conceptual model has six broad domains of quality of life and 24 facets within each domain. These six domains are physical health, psychological health, level of independence, social relationships, the environment, and spiritual well being. Although no published information is available as to how these domains should be defined from the WHOQOL's perspective, the facets that were included in each domain delineate the main components of the concept of quality of life. No published information was available as to how the WHOQOL Group depicted its conceptual model. Hence, Figure 1 is an attempt to delineate the conceptual model as derived from the available information. The figure also provides more information on the aspects/ facets included in each domain.

The conceptualization of quality of life described above is compatible with the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001a), a framework from which to understand health and disability. Both the ICF and the WHOQOL model were used to guide this study as the use of the two models facilitated a more in depth exploration of outcomes, quality of life and other environmental factors expected to be affected by Asperger Syndrome (WHO, 2001b). The ICF is not explicit enough to understand a specific area such as quality of life and the WHOQOL model is not broad enough to help understand the whole domain of outcomes. The ICF and the WHOQOL model both take into account social aspects of functioning and the impact that a disability such as Asperger Syndrome has on functioning and quality of life. Both recognize that the context or environment, and not the person alone, are influential on health and quality of life. The ICF and the WHOQOL were both designed for describing and comparing health and quality of life of populations in an international context. Both try to overcome the 'impairment' focus by providing perspectives as to how health care interventions can be targeted to optimize the person's ability to remain in the workforce, live a full life in the community and have a satisfactory quality of life as identified by the individual (WHO, 2001b).

As a classification, ICF defines components of health and considers the consequences of disease or other health conditions on activities and participation (related to the societal context). The term *functioning* serves as an umbrella term that encompasses all body functions and structures, activities and participation. Similarly, *disability* serves as an umbrella term for impairments, activity limitations or participation restrictions (WHO, 2001b). Impairments include problems in the body functions or structures due to a significant deviation or loss of these body functions and structures. Activity limitations include difficulties an individual may have in executing these activities. Participation restrictions are the problems that an individual may have in involvement in life situations (WHO, 2001b). Hence, ICF takes into account the social aspects of disabilities and provides mechanisms to document the impact of the social and physical environment on a person's functioning. Furthermore, Barbotte and colleagues (2001) argue that the determinants of quality of life (e.g., social relationships, physical health, psychological state, level of independence) are influenced by the disability; that is, any impairment, activity limitation, or participation restriction suffered by an individual. Therefore, quality of life is a consequence of functioning or disability. In sum, both the ICF and the WHOQOL model were used as the overall guiding framework to ensure a clear understanding of the impact of a disorder such as Asperger Syndrome; a health condition that has an obvious impairment at the level of function; on health and quality of life as the two concepts are not interchangeable.

Figure 1. **World Health Organization Conceptual Model**

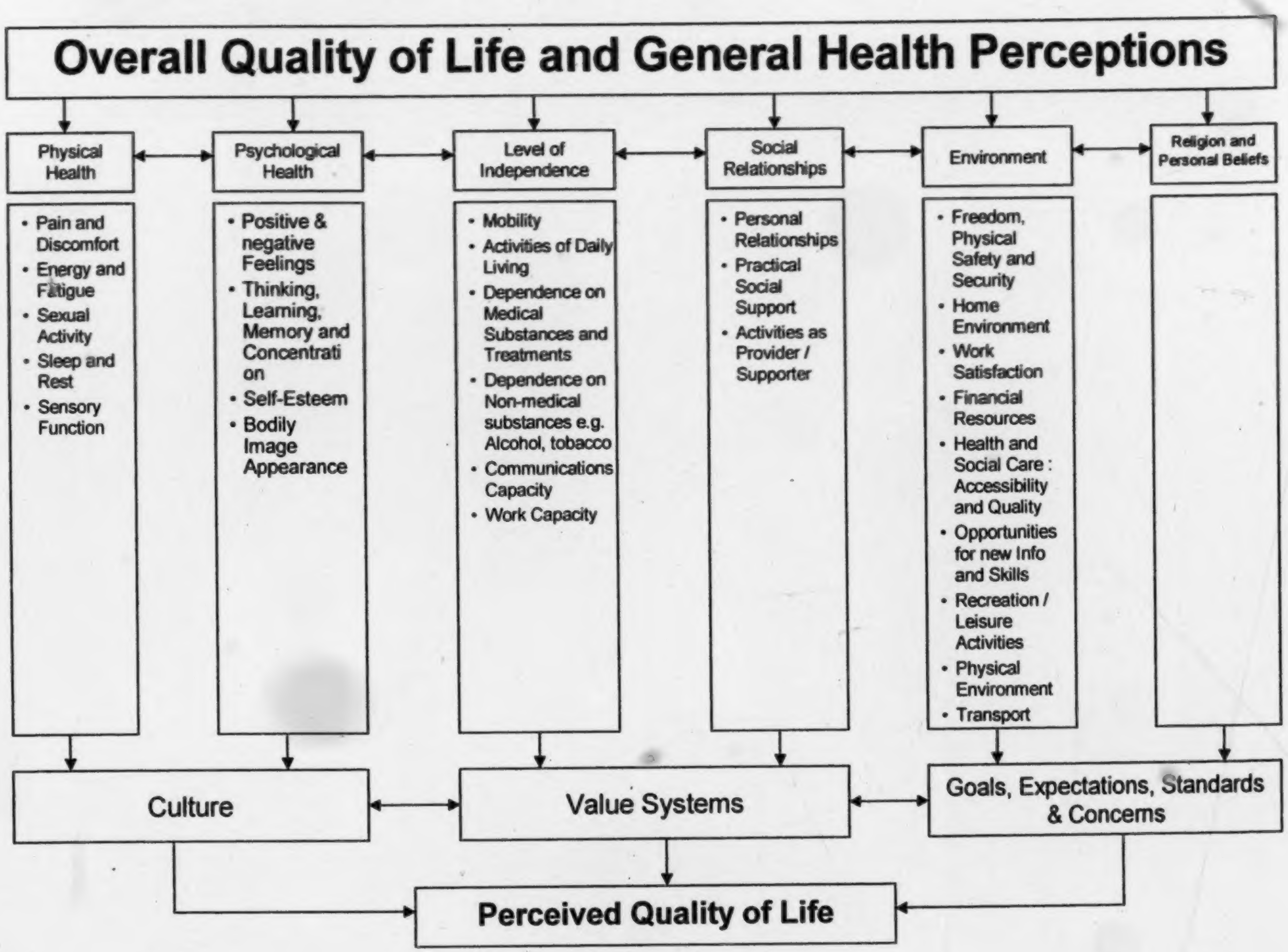
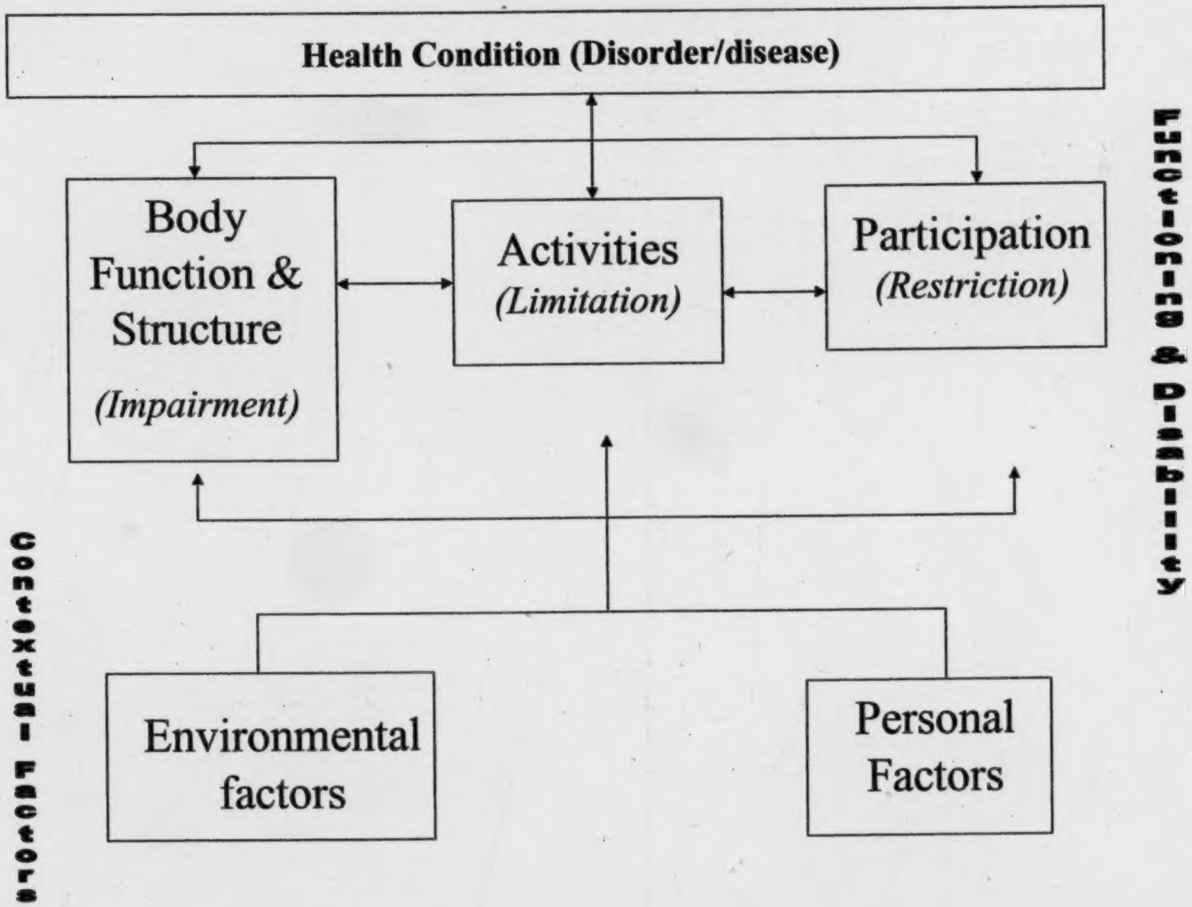

Overall Quality of Life and General Health Perceptions
Physical Health
Psychological Health
Level of Independence
Social Relationships
Environment
Religion and Personal Beliefs
• Pain and Discomfort
• Energy and Fatigue
• Sexual Activity
• Sleep and Rest
• Sensory Function
• Positive & negative Feelings
• Thinking, Learning, Memory and Concentrati on
• Self-Esteem
• Bodily Image Appearance
• Mobility
• Activities of Daily Living
• Dependence on Medical Substances and Treatments
• Dependence on Non-medical substances e.g. Alcohol, tobacco
• Communications Capacity
• Work Capacity
• Personal Relationships
• Practical Social Support
• Activities as Provider / Supporter
• Freedom, Physical Safety and Security
• Home Environment
• Work Satisfaction
• Financial Resources
• Health and Social Care : Accessibility and Quality
• Opportunities for new Info and Skills
• Recreation / Leisure Activities
• Physical Environment
• Transport
Culture
Value Systems
Goals, Expectations, Standards & Concerns
Perceived Quality of Life

Figure 2. **International Classifaction of Funcitoning, Disability and Health**


Health Condition (Disorder/disease)
Body Function & Structure
(Impairment)
Activities
(Limitation)
Participation
(Restriction)
Functioning & Disability
Environmental factors
Personal Factors
Contextual Factors

Asperger Syndrome and Quality of Life

In the following section, Asperger Syndrome is defined. The WHOQOL model of Quality of Life is used to discuss the literature related to persons with Asperger Syndrome. The physical domain is not covered in detail, as to date; no literature indicates that Asperger Syndrome has a great influence/impact on physical health. The spiritual domain as outlined by the WHOQOL Group is not discussed because this was not the main focus of the proposed study.

Asperger Syndrome: definition and prevalence

Asperger Syndrome is a pervasive developmental disorder characterized by impairment in socialization, communication and behaviour. Individuals with Asperger Syndrome typically lack developmentally appropriate social skills and have a limited ability to take part in reciprocal communication (Barnhill, 2001). Moreover, they do not seem to understand the unwritten rules of communication and conduct. Individuals frequently have difficulty using and understanding eye contact, gestures, and facial expressions in communication with others (APA, 2000). According to Attwood (1998), due to difficulties in empathizing and taking others' perspectives, many young adults with Asperger Syndrome experience difficulties making and keeping friends, despite having a desire to do so. In addition, many individuals have unusually intense and often peculiar areas of circumscribed interests. For many of them, this area of interest is the only topic that motivates them to interact with others, and these individuals seem to have difficulties in understanding when it is appropriate to discuss these specific topics (Adreon & Stella, 2001). Difficulties in shifting attention and cognitive rigidity are also characteristics of the syndrome. Individuals have a strong preference for predictability (Bolick, 2001) and changes in routines, scheduled events or activities can have a profound negative effect on them. In addition, learning disabilities and motor clumsiness frequently accompany Asperger Syndrome (Szatmari, 1991). Finally, recent reports suggest that individuals with the syndrome appear to be more at risk for depression (Ghaziuddin et al., 1998).

According to Barnhill (2001), the prevalence of Asperger Syndrome appears to be increasing. Fombonne (2001) studied the prevalence rates and estimated it at 2 per 10,000. Yet, according to the Diagnostic Statistical Manual of mental disorders – text revision (DSM-IV-TR), definite data regarding the prevalence are lacking (APA, 2000). This could be due to the fact that there is currently no agreement on the definition and diagnostic criteria for Asperger Syndrome between the DSM-IV and the International Classification of Disabilities - Tenth Edition (ICD-10) (WHO, 1990) criteria and its boundaries with high-functioning autism. The DSM-IV-TR defines Asperger Syndrome as a pervasive developmental disorder separate from autism (APA). The main characteristics distinguishing the two groups are the presence of normal or near-normal intelligence and language abilities in all persons with Asperger Syndrome versus a range of intelligence and language levels in those with autism. The second difference noted by many researchers and clinicians is the greater degree of social unresponsiveness seen in individuals with autism (APA). Age of onset is a third difference. Because the distinction between Asperger Syndrome and autism has been made only recently (Howlin, 2000), past research has included persons with Asperger Syndrome and high functioning autism in the same studies. This has made it very difficult to distinguish the long-term outcomes of persons with autism from those with Asperger Syndrome and makes it necessary to review some of the literature based on mixed samples here. It is important to assess how individuals with Asperger Syndrome develop over time in order to provide them with the necessary support to improve their quality of life.

Psychological Health and Asperger Syndrome

The literature indicated that psychological health is an essential component of a life worth living. One can argue that it is unlikely that many people would define a life characterized by joylessness, low self-esteem, isolation, and depression as a 'satisfactory life'. Assmann, Avis & Smith (1999) found that health status was mainly associated with physical functioning, while quality of life was more related to mental health. Research indicated that adolescents and young adults with Asperger Syndrome are prone to depression and anxiety (Brereton, Einfield, Gray & Tonge, 1999; Ghaziuddin et al., 1998; Tantam, 2000). Ghaziuddin et al. argued that depression might be linked to difficulty in coping and the resulting social stigma experienced by the young adults, or it may result from biological or genetic factors that may, in some way, be linked to the pathogenesis of the syndrome. According to Goode and Howlin (1998), the rate of affective disorders may be as high as 33%. Given the absence of large-scale studies such statistics remain tentative. Nevertheless, it is generally known that depression and anxiety disorders have an enormous effect on one's quality of life. Hence, it was suspected that individuals with Asperger Syndrome would be more likely to rate their overall quality of life lower due to psychological health problems.

Level of Independence and Asperger Syndrome

'Level of independence' is one of the WHOQOL domains of quality of life that addresses the level of functioning of an individual. Investigating certain aspects of this domain such as education, employment, living arrangements and mobility provides more information on the long-term consequences of this disorder for the individual's quality of life. Income was included; even though it is listed under environment; as it is often a result of employment and it influences how independent one can or cannot be (i.e. having enough financial resources to be able to rent an apartment, pay the expenses…). Outcome literature related to the level of independence of individuals diagnosed with Asperger Syndrome was reviewed.

While there is a steadily increasing body of research on the topics of autism and Asperger Syndrome, relatively little has been written about outcomes related to independence in adulthood (Goode & Howlin, 1998). The available accounts of outcome in adult life present a confusing picture to families and health care professionals for several reasons. Drawing conclusions is difficult due to the limited numbers of studies, the small sample sizes, the variability of outcome measures, and the heterogeneity of subjects, especially in regards to diagnosis (Goode & Howlin). Follow-up studies that had participants with similar cognitive abilities failed to distinguish consistently between high functioning individuals with autism and those with Asperger Syndrome. Hence, there is a need for follow-up studies that include only individuals with Asperger Syndrome and to use clear diagnostic criteria with regards to the syndrome. This would make it possible to trace the course and impact of the disorder over time in relationship to quality of life, and more specifically to the individual's level of independence.

Dalrymple and Ruble (1996) argued that previous outcome studies have used narrow definitions of outcomes focusing on only a few variables or broad general categorizations. According to them, the conclusions in these studies in regards to the participants' overall outcome were based on whether the outcome was 'good', 'moderate', or 'poor'. 'Good' was defined as the achievement of independence, the development of a normal or near normal social life and satisfactory functioning at work and/or school. Because most individuals with Asperger Syndrome continue to struggle with social relationships and need individualized supports, this outcome was rare. The majority of individuals with Asperger Syndrome rely heavily on the support of their families and remain highly dependent (Dalrymple & Rube; Howlin, 2000; Howlin & Mawhood, 1999). According to Howlin, only a minority of the individuals studied in follow-up studies were employed or able to continue further education and live independently without the support of others. Dalrymple and Ruble found in their study that individuals that appear to do well have strong social support. Consequently, the utility of traditionally defined outcomes is questioned. They suggest that parents, educators and researchers need other frameworks such as quality of life to conceptualize a 'good outcome'.

Work capacity is an aspect of the domain 'level of independence' that appears to be affected by Asperger Syndrome. Although many people successfully complete mainstream education and may go on to obtain college or university qualifications, follow-up studies indicate that employment levels in adulthood are disappointing (Goode & Howlin, 1998). According to Howlin and Mawhood (1999), jobs tended to be of low status and/or to end prematurely, often because of difficulties related to social competence. Howlin (1997) argued that the failure to make appropriate use of training and skills, or to find suitable work, sometimes despite many years of trying, results in frustration, loss of self-esteem and for some, entry into a cycle of anxiety and depression or other psychiatric disturbance. On the other hand, Howlin and Mawhood found that with appropriate strategies such as supported employment, individuals with Asperger Syndrome can find and maintain suitable employment, which may have an impact on the quality of life of these individuals.

Mobility or more specifically being able to use the public transport system and to drive a car, is another aspect of the domain 'level of independence.' No information is currently available as to how this aspect is affected by Asperger Syndrome.

Social relationships and Asperger Syndrome

The social relationship domain of quality of life include 3 facets; personal relationships, sexual activity and social support. Social relations and social skills are essential to the determination of quality of life. These areas are usually affected by the impairments associated with Asperger Syndrome. Findings of follow-up studies reported that socially, individuals with Asperger Syndrome continued to have marked difficulties. Alisanski, Amanullah and Church (2000) found that social abilities were highly variable but remained the greatest challenge. They found that as the children matured, most of them desperately wanted to fit in with their peer group but lacked the skills and social knowledge required.

According to Goode and Howlin (1998), most adults with Asperger Syndrome can be described as 'loners' and few adults marry or have friends. They found that only 15-20% of participants had friendships that involved both selectivity and shared enjoyment. Others have argued these results as very optimistic as the social contacts of individuals with Asperger Syndrome often result from their special interests and skills rather than close friendships (Howlin, 2000; Tantam, 1991). No information is currently available as to whether the friendships resulting from these special interests are perceived as less supportive or satisfactory. Hence social support needs to be investigated in relationship to the quality of life of individuals with Asperger Syndrome. Tantam (2000) argued that some people with Asperger Syndrome seem to cut themselves off from others, taking refuge in a special world of routines and private preoccupations. He argued that for these individuals, close friendships or sexual relationships hold little attraction.

Some individuals with Asperger Syndrome become painfully aware of their desire for closeness and may succeed in making friendships with people of their own sex who often have some social difficulties themselves. Tantam argued that sexual relationships are much harder to achieve, and that many people with Asperger Syndrome find their already low self-esteem further eroded by rejections. Failing at other social tasks may continue throughout life and may be a constant source of distress (Tantam, 2000) and therefore affect the quality of life of these young adults.

Environment and Asperger Syndrome

The environmental domain of quality of life addresses several components such as safety, opportunities for acquiring new skills, financial resources, accessibility to health care and recreation or leisure. Again, financial resources were included under the domain level of independence. Only leisure as part of the environment is addressed in detail.

Tremendous efforts within the field of disabilities in recent years have led to people with disabilities securing better educational, vocational, and accommodation opportunities. Still, the importance of leisure and social activities has not been adequately recognized (Fine, 1996) although it appears to be a fundamental component related to quality of life (Connolly & Law, 2001). Hegenauer and Marinoble (1988) reported the growing need to examine key variables in transition planning for young people with disabilities. Students with developmental disabilities, rating the importance of the training they received in school, identified elements that were most helpful to them in securing quality living. They rated social skills and independent living training along with the use of leisure time as more valuable to them than traditional academic training.

Leisure is often thought of as occupying oneself in one's free time. However, scholars argued that leisure is more than occupying oneself. Fine (1996) argued that leisure has to do with freedom, choices, and growth. Surprisingly, follow-up studies for individuals with Asperger Syndrome have never investigated this area. For people with Asperger Syndrome, leisure activities may be important in decreasing feelings of loneliness, boredom and isolation and increasing their quality of life.

Physical health and Asperger Syndrome

Persons with Asperger Syndrome were not expected to have impairments that interfere significantly with their quality of life related to physical health. Persons with Asperger Syndrome have been described as being clumsy. According to the DSM-IV-TR, motor clumsiness and awkwardness may be present in 50% to 90% of individuals with Asperger Syndrome but it is usually relatively mild and was therefore not expected to have a strong influence on their quality of life as young adults (APA, 2000).

The physical domain of quality of life addresses items such as pain and discomfort, dependence on medical treatment, activities of daily living, work capacity, energy and fatigue, mobility, sleep and rest. Some researchers such as Butler and Ghaziuddin (1998) argue that clumsiness of movements, which is a common feature of Asperger Syndrome (APA, 2000), could have an influence on one's ability to function satisfactorily in life.

Clumsiness can be defined as an impairment of skills on standardized tests of motor functioning, below the level expected based on intelligence and in the absence of a known neurological disease (Butler & Ghaziuddin, 1998). According to Myles and Simpson (2001) the implications of such deficits are significant as being awkward and clumsy could make it difficult to participate successfully in games requiring motor skills. Thus, poor physical abilities and performance exacerbate their social deficits. Fine motor difficulties may interfere with a variety of school activities, such as handwriting, art, and industrial arts (Myles et al., 2000). However, reliable estimates of the prevalence of motor impairments are not available (Ghadziudden, Ghadziudden & Tsai, 1992; Gillberg, 1989; Miyahara, Isujii, Hari, Nakanishi, Kagayama & Sugiyama, 1997). Furthermore, comparison between existing studies of clumsiness is difficult, particularly because consistently agreed upon criteria for the diagnosis of Asperger Syndrome do not exist (Howlin, 2000) and few studies use the same criteria (Ghazuiddin et al., 1992; Smith, 2000).

Summary

Asperger Syndrome is a chronic disorder with persistent, residual impairments in sociability that has an impact on a number of areas associated with quality of life. While some researchers agree that there is a gradual overall improvement in symptoms over the years such as an increase in adaptive skills, the majority of these individuals rely heavily on the support of their families and remain highly dependent (Dalrymple & Ruble, 1996; Howlin, 2000). Quality of life and factors associated with quality of life for persons with Asperger Syndrome has not been compared to that of individuals in the same age range without disabilities. Information of this nature would be useful to many parents and practitioners. In addition, Dalrymple and Ruble stated that quality of life is best achieved by social support, yet social support in relationship to quality of life for young adults with Asperger Syndrome remains an area for investigation.

Social Support and Quality of Life

In the following section, social support is defined. The relationship between social support and quality of life is highlighted. To date, no literature is available on social support and individuals with Asperger Syndrome; therefore, relevant literature on disabilities in general is discussed.

Defining Social Support

Social support can be defined as interactions that lead people to believe they are cared for, loved, esteemed and valued and that they belong to a network of communication and mutual obligation (Friedland & McColl, 1989). According to McColl (1997) researchers have come to the agreement that social support is a multidimensional concept and that the term may be thought of as an umbrella term, covering four dimensions. These four dimensions are (1) network structure, (2) types of support (3) sources of support and, (4) evaluation of support.

The first dimension is network structure. It includes structural characteristics of support that can be investigated by measuring network availability, network size, network density and dispersion. Hence, the social network can be described as a structured representation of an individual's social world; it is comprised of an individual's social relationships and provides a framework for the provision of social support (Ferry & Rauch, 2001). As well, a social network is considered an important indicator of community integration (Ferry & Rauch).

The second dimension is type of support. Caplan (1974) conceptualized types of support in three ways. Emotional support includes the provision of love, care and concern. Informational support entails the extending of information and guidance relevant to a stressful situation (i.e., a transition into adulthood). Tangible support includes acts to assist an individual in daily functioning. Each type of functional support may contribute to psychological well being and therefore have an impact on the quality of life of the individual receiving the support.

Sources of support represent the third dimension of social support. Sources are divided primarily into formal and informal sources. According to McColl (1997), formal sources of support are those every one should have such as access to professionals when needed. Informal sources are those sources to which individuals uniquely have access because of who they are.

Evaluation of support is the fourth dimension that may be used to characterize social support. It is defined as the extent to which support is perceived as positive, supportive, helpful and satisfactory. McColl argued that this dimension is similar to what other researchers call adequacy or satisfaction with support. This focus on perceived support is justified according to McDowell and Newell (1996) as the fact that a person does not perceive support does not mean that the person is unsupported but rather it is not perceived as adequate or supportive enough.

Social Support and Quality of Life

A substantial body of research suggests that social support plays a significant role in protecting adults from stress and that low support has harmful effects on health and well-being (Anderson, Naughton, Rapp, Schmidt & Shumaker, 1998). In addition, social support contributes to positive adjustment in the child and adult and encourages personal growth (McDowell & Newell, 1996). Social support and social networks, in conjunction with other variables have been identified as predictors of health, quality of life and other outcomes (Israel, 1983) for persons with disorders such as traumatic brain injury (Smith, Magill-Evans & Brintnell, 1998). Ferry and Rauch (2001) reported that the nature of the relations between social support, social networks and health outcomes is the same in other populations. As this still needs to be investigated for persons with Asperger Syndrome, the literature related to persons with disabilities in general is reviewed.

One of the most notable observations about the social networks of people with disabilities is their size. According to Antonucci and Jackson (1990), the networks of people with disabilities are smaller, less dense and less complex than those of persons without disabilities. While most adults have networks of 8 to15 individuals, estimates for those with disabilities vary widely (McColl, 1997). Conway and Wortman (1985) found in their study that the disability itself imposes constraints on interactions with the support system. They stated that social barriers such as inability to easily maintain normative social behaviour, might limit the ability of someone with a disability to sustain a social network. Research has found positive relationships between social competence, social networks and social support for people with schizophrenia (Baglioni, Hayes, Jackson, Madden & Macdonald, 1997). Baglioni and colleagues found in their study that people with schizophrenia who were more socially skilled had larger social networks; conversely, people that had more problems with their social skills had smaller social support networks. They also found that more socially skilled people did not perceive greater support from these networks than did less socially skilled. This was the same for people with problems in socialization. They argued that it is possible that people with schizophrenia obtain support, regardless of their ability to establish or maintain social relationships. Hence, small networks can be perceived as being supportive. However, there is a diversity of opinions in the empirical research as to whether objective characteristics of social support or the subjective or qualitative characteristics as interpreted by the individual have the strongest relationship with well being (Israel, 1983). For this reason, more research is needed to understand the relationship between social support, support network and quality of life.

According to Knox and Parmenter (1993), the composition of networks for people with disabilities is different from those of the general population as it contains family members to a far greater extent, a finding supported by McColl (1997). It was expected that this would be true for persons with Asperger Syndrome as well. Dalrymple and Ruble (1996) found in their study that individuals with autism had better relationships with parents and adults than with peers and siblings. These findings confirmed those of previous research (Howlin, 1986).

Different types of support have different relationships with outcomes such as quality of life, adjustment and occupational function (McColl, 1997). Types of support include tangible, informational and emotional support. According to McDowell and Newell (1996) the empirical evidence shows that these types of support help people in coping with stress or illness, although the mechanisms involved are not clear. While emotional support has consistently shown a positive relationship to outcomes, researchers found that the clients do not uniformly perceive other types of support as supportive. Hence, investigating what was perceived as more supportive among young male adults with Asperger Syndrome, especially in relationship to their quality of life might provide valuable information for intervention.

- Sources of support, formal and informal are known to delay or reduce the risk of institutionalization and generally increase the well being and the degree of satisfaction of elderly in the community. In an analysis of the sources of support in stroke recovery, Friedland and McColl (1987) have found that the types of social support that are the most influential are support from a close, personal source, support from individuals in the community and the satisfaction with support. In addition, they found that the impact of professional sources of support was minimal. In contrast, Anderson (1993) assessed differences in perceived social support between post-secondary students with disabilities and non-disabled students and emphasized the importance of professionals in overcoming the potential barriers to post-secondary education. No information on sources of support was available for individuals with Asperger Syndrome. Yet, this information might guide parents and health professionals in providing more appropriate services for these young adults with Asperger Syndrome in order to improve their quality of life.

The evaluation of support is defined as the extent to which support is perceived by the individual as positive, supportive, helpful and satisfactory (McColl, 1997). According to Israel (1983), these subjective or qualitative characteristics of support, as interpreted by the individual, could have the strongest relationship with well being and could therefore affect the quality of life of these individuals.

Summary

The process through which social support and quality of life are related for individuals with Asperger Syndrome has not been addressed in the literature. Furthermore, the results obtained from the studies of social support in general endorse further inquiry into the relationship of social support to quality of life. Because social support has been shown to act as a buffer against stress in a variety of situations, research needs to be conducted to confirm whether persons diagnosed with Asperger Syndrome who experience greater social support also report greater quality of life.

Summary

The WHOQOL conceptual model and the ICF provide a guiding framework to understand the link between quality of life, social support and other outcome variables. Although there are objective indicators correlated with quality of life perceptions such as income, research shows general agreement that quality of life is essentially subjective in nature and is therefore assessed using subjective measures. Investigating how young adults are doing in regards to variables associated with quality of life such as social relationships, level of independence, physical and psychological health and the environment might provide more insight as to how Asperger Syndrome has an impact on these young men's lives. Further study is needed to understand the relationship between subjective factors such as quality of life and more objective features of individuals' lives such as their overall outcome. This will be of great value as a better understanding of these dynamic factors is essential in effective program planning and providing appropriate interventions. Furthermore, identifying characteristics, which are associated with variations in quality of life, may provide insight into areas of the client's life that could be altered by rehabilitation intervention to directly enhance their quality of life.

CHAPTER TWO

METHODS AND PROCEDURES

Study Design

A quantitative approach to measurement was used to allow the results to be compared with those in other reports in the literature. The design of this descriptive, comparative study allowed for an exploration of the quality of life of individuals affected by Asperger Syndrome in relationship to their general outcomes and social support.

This study used participants of the Koning and Magill-Evans study (2001a) that was conducted approximately six years ago. The follow-up of these young men allowed gathering of information regarding the course and impact of Asperger Syndrome on individuals' quality of life.

The Koning and Magill-Evans sample (2001a) was exceptional in that it consisted only of persons with Asperger Syndrome and did not include higher functioning individuals with autism, making it very homogeneous. This homogeneity was a particular strength as most previously conducted outcome studies contained individuals with Asperger Syndrome as well as high functioning individuals with autism. The clinical group, consisting of individuals with Asperger Syndrome, was matched to a control group that included individuals without Asperger Syndrome, allowing information to be obtained on how Asperger Syndrome influenced outcome variables and quality of life.

Sample characteristics

The original total sample included 57 individuals between 12 and 15 years of age. All spoke English as their first language. The sample was divided into 2 groups: a clinical group including participants with Asperger Syndrome, and a control group of participants without Asperger Syndrome.

Clinical Group

The clinical group in Koning and Magill-Evans' study (2001a) was comprised of 29 boys who were identified by psychiatrists in Edmonton as having social skills deficits consistent with a diagnosis of Asperger Syndrome as defined by the DSM-IV (APA, 1994). The sample was recruited by contacting all psychiatrists providing services to this population.

To verify the diagnosis of Asperger Syndrome, the referring psychiatrist completed the Ehlers and Gillberg's checklist for screening of Asperger Syndrome on each participant. Scores ranged from 20 to 51 out of a possible 54 on the Asperger's Syndrome Screening Questionnaire (AASQ) (Koning & Magill-Evans, 2001b).

The original study included only boys because the diagnosis of Asperger Syndrome is much more common in boys than in girls, and the authors of the original study did not want to confound the results with gender. The sample was further limited by excluding subjects who had been diagnosed with psychosis at any time.

Control Group

The control group consisted of 28 boys who were matched on the basis of their age and Wechsler Intelligence Scale for Children (Third Edition) (WISC-III: Wechsler, 1991) vocabulary test scores. The participants were recruited from several community schools in the Edmonton area. Teachers identified these students. Inclusion criteria were (1) the students had to speak English as their first language, and (2) the students could not have difficulties with social skills or peer relationships. These students also had to be average and not particularly socially skilled (as defined by the student's teacher).

At the time of the previous study six years ago, the boys in both groups did not differ in regards to the vocabulary sub-test of the WISC-III (Wechsler, 1991), age, or estimates of family socio-economic status (SES). SES was determined using the Socio-economic Index for Occupations in Canada (Blishen, Carroll, & Moore 1987).

As this study was conducted approximately 6 years after Koning and Magill-Evans's study and tried to trace its participants, sample attrition was anticipated resulting in a limiting of the number of variables included in analyses. Regardless of this limitation, this sample was still chosen for follow-up because it:

- included persons who have met the most stringent criteria for Asperger Syndrome, a population very difficult to recruit as young adults;
- included a matched control group; and
- allowed future secondary data analysis relating variables measured in adolescence to outcome during early adult life.

Procedures and Measures

The participants of Koning and Magill-Evans' (2001b) study were contacted after approximately six years by Koning to obtain permission for the investigator to contact them (Appendix A). When ethics approval was received and informed consent (Appendix B) forms were signed, the participants were assessed.

Three tools were used for the data collection: two self-administered questionnaires and a semi-structured interview. The World Health Organization Quality of Life assessment, brief version (WHOQOL-BREF) and the Perceived Support Network Inventory (PSNI) were sent out to the participants. The participants completed both questionnaires prior to the interviews so that the questionnaires could be collected at the time of the interview.

The World Health Organization Quality of Life – Brief version (WHOQOL-BREF)

No quality of life measures have been developed specifically for individuals with autism or Asperger Syndrome. Therefore, a generic, non-disease related quality of life measurement was used. The WHO developed the WHOQOL-BREF, an abbreviated version of the WHOQOL-100 (WHOQOL Group, 1998a). During the development of the WHOQOL-100, focus groups of patients, health professionals and 'healthy' participants (45% of the participants had no health problems) proposed items that were selected. A five-point quasi-interval Likert response scale was used for responses. The questionnaire was administered simultaneously in 15 centres worldwide (N = 4802). The WHOQOL Group had noted that the WHOQOL-100 might be too lengthy for some uses.

In constructing the WHOQOL-BREF, data were taken from twenty field stations situated in eighteen countries (Bonomi, Bushnell, Goodman, Martin, Patrick & Wild, 1997) to form an alternative brief instrument for measuring quality of life. Brevity is important as return rates are higher when short quality of life measures are used (WHOQOL Group, 1998b). One item from each of the 24 facets contained in the original WHOQOL-100 was included (WHOQOL Group, 1998b) as well as two additional questions: Question 1 asks about an individual's overall perception of their quality of life, and Question 2 asks about an individual's perception of his or her health. The 24 items form four domain scores with an unequal number of items in each domain. Domain scores are scaled in a positive direction with higher scores denoting higher domain score. Explicit instructions for checking and cleaning data and for computing domain scores are provided (Appendix C). While the initial conceptual framework for the WHOQOL-100 included six domains, subsequent data analysis yielded a four-factor model. The four-factor model was shown to be superior to the six-factor model in terms of 'degree of fit', for both ill and well populations (WHOQOL Group, 1998a). On the basis of these analyses, the WHOQOL-BREF is a 26-item questionnaire covering four domains: Physical, Psychological, Social and Environmental domains (Figure 3.0). Spirituality is addressed as an item under the psychological domain. The WHOQOL-BREF is a multi-dimensional profile for subjective assessment of quality of life. This generic measure was designed for use with a wide spectrum of psychological and physical disorders and has been tested on individuals over a wide range of ages (Couston, Cossar, Hayes, O'Carroll & Smith, 2000).

The Victorian Validation Study (VVS) was conducted by the Centre for Health Program Evaluation, Melbourne (Melbourne WHOQOL Field Study & Centre, 2002). The study provided WHOQOL-BREF data based on random sampling of the population, which are the only published normative data available. The sample consisted of (a) randomly selected community members weighted by socio-economic status to achieve representativeness of the Australian population (N= 392), (b) outpatients attending 2 of Melbourne's largest public hospitals (N=334), and (c) inpatients from 3 hospitals in Melbourne (N=266). Mean scores for the four domains ranged from 72 (social) to 80 (physical). Mean scores for the two overall quality of life items were 4.3 for item 1 (quality of life) and 3.6 for item 2 (health). Being based on a stratified community sample, these VVS data provides an indication of Australian norms for the WHOQOL-BREF (Melbourne WHOQOL Field Study & Centre).

Discriminant validity of the WHOQOL-BREF was assessed by analyzing WHOQOL-BREF scores according to the health status of the respondents. Angermeyer, Killian & Matschinger (2001) conducted a study where they examined the impact of chronic illness on subjective quality of life. They compared the general population and hospital inpatients with somatic and psychiatric diseases. They found that mean scores and standard deviation scores (SD) for individuals diagnosed with schizophrenia were significantly lower in comparison with the norms. As well, the data collected in the VVS study showed significant differences between groups for all four domains and both individual items. Overall, the findings of the VVS study supported the discriminant validity of the WHOQOL-BREF. The physical domain and the 2 global items appear to discriminate well across the full health spectrum, from 'well' to 'ill'. While the psychological, social and environment domains likewise discriminate between people who are well and those who are ill, there was a lack of discrimination at the bottom end of the spectrum, i.e. between those who are ill (outpatients) and those who are very ill (inpatients). The VVS data supported previous results by Billington, Carlson, Orley and Saxena (2001).

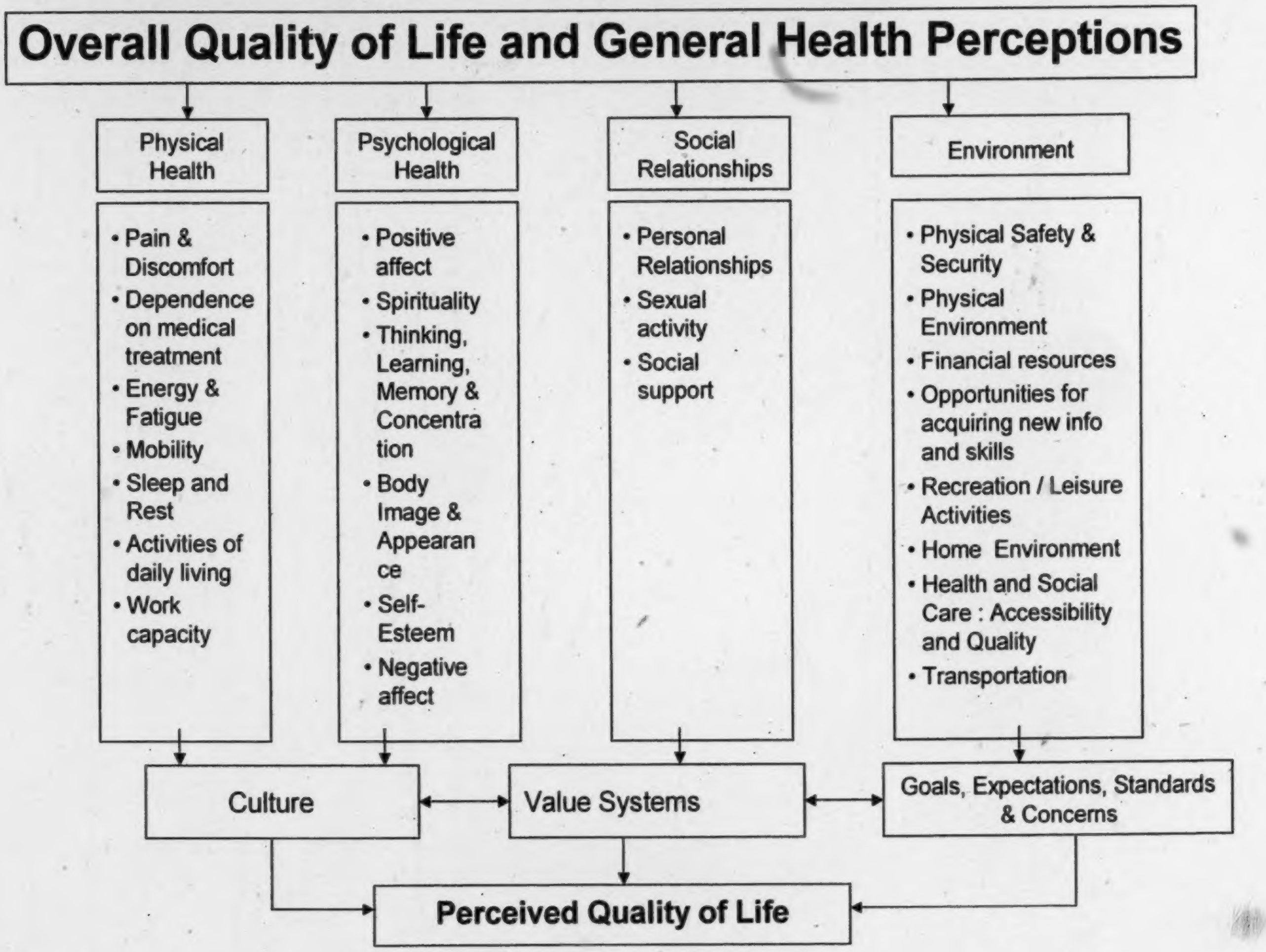
The WHOQOL-BREF appears to be responsive to clinically meaningful change for the physical, psychological and environmental domains (Bonomi et al., 1997). The social domain is less sensitive for the persons in the normative sample, which included healthy as well as sick persons across the life span.

Construct validity for the WHOQOL-BREF was investigated through correlational analysis using 3 commonly used quality of life assessment tools as the external standard; the Short Form 36 Health Status Questionnaire (SF-36), the European Profile of Quality of Life (EQ-5D), and the Assessment of Quality Of Life (AQOL).

Since each of these instruments is purported to measure health-related quality of life, high correlations would support the construct validity of the WHOQOL-BREF. More specifically, some of these instruments measure certain aspects of health related qualify of life as reflected in the separate WHOQOL domains and thus might be regarded as a 'gold standard' for that particular domain. Correlations between the WHOQOL-BREF and these measures ranged between .30 to .80 for the physical domain, between .20 to .70 for the psychological domain, between .04 to .48 for the social relationship domain, and between .17 to .55 for the environment domain. For the overall quality of life item, correlations ranged from .19 to .50 and for the overall health item, from .24 to.58 (Melbourne WHOQOL Field Study & Centre, 2002). On the whole, according to the Melbourne WHOQOL Field Study Centre, the correlations with other instruments were significant but moderate for social relationships and environment, suggesting that these two domains and the other health related quality of life instruments are measuring different but related aspects of quality of life.

This measure has good psychometric qualities. Cronbach alpha values for each of the four domain scores ranged from .66 (for social relationships) to .84 (for physical health), demonstrating internal consistency. The interval between test and retest ranged from 2 to 8 weeks. The test-retest reliabilities were .66 for the physical, .72 for the psychological, .76 for the social and .87 for the environmental domains. Domain scores correlated at around .90 with the WHOQOL-100 (WHOQOL Group, 1998a). The reading level of the WHOQOL-BREF with Flesch-Kincaid Grade equalled 5.1 and the readability is 77.9.

Figure 3. World Health Organization Conceptual Model – Brief Version



Overall Quality of Life and General Health Perceptions
Physical Health
Psychological Health
Social Relationships
Environment
• Pain & Discomfort
• Dependence on medical treatment
• Energy & Fatigue
• Mobility
• Sleep and Rest
• Activities of daily living
• Work capacity
• Positive affect
• Spirituality
• Thinking, Learning, Memory & Concentra tion
• Body Image & Appearan ce
• Self-Esteem
• Negative affect
• Personal Relationships
• Sexual activity
• Social support
• Physical Safety & Security
• Physical Environment
• Financial resources
• Opportunities for acquiring new info and skills
• Recreation / Leisure Activities
• Home Environment
• Health and Social Care : Accessibility and Quality
• Transportation
Culture
Value Systems
Goals, Expectations, Standards & Concerns
Perceived Quality of Life

The Perceived Support Network Inventory (PSNI)

The PSNI (Oritt, Paul & Behrman, 1985) was based upon the theoretical work of Heller and Swindle (1983). Heller and Swindle described the social support process as an interaction between environment and person variables occurring across time. They suggested that the support received by an individual during the experience of a stressful event such as a transition into adulthood, was a function of the "availability of supportive structures in the environment interacting with individual skills and competencies in accessing and maintaining supportive relationships that present themselves in the environment" (Heller & Swindle, p. 91). They proposed that support received at any given time was dependent not only on currently available support but also on the individuals' historical experience with support availability, the degree to which the individual has the interpersonal skills needed to access and maintain support in a relationship and the actual support-seeking behaviours exhibited by the individual during times of stress. Heller and Swindle's social support model distinguished among social network characteristics, perceptions of social support, and support seeking behaviours.

The PSNI measures social network characteristics, perceptions regarding social support, and support seeking activities. It is a self-administered questionnaire that yields scores for the following dimensions: (1) size of supportive social network, (2) initiation of support seeking behaviour, (3) perceived availability of support, (4) satisfaction with support, (5) perceived multidimensionality, (6) perceived network reciprocity and (7) perceived network conflict. The PSNI consists of 2 parts, resulting in a total social support score and six sub-scale scores (Appendix D).

In the first part, the participants identify up to12 people that they would turn to in times of stress. This part, called support network, identifies the participants' perceived network size. The total number of contact people was the "perceived network size." As well, the participants assign the earlier identified network members to relationship categories, i.e., spouse or partner, family member, friend, co-worker, professional, religious leader and self-help group. The number of people for each relationship category is recorded.

The second part of the PSNI captures more specific information about the person's support network. The participants rate each person they identified in the first part on a 7-point Likert scale on the incidence of the following elements resulting in six sub-scale scores. Initiation of support investigates the extent to which an individual actively seeks support from his or her network members. Perceived availability of support examines how readily available network members are for providing support. Satisfaction with support is the third sub-scale and examines how satisfied someone is with the support provided by his or her network member in reducing stress and restoring the emotional and instrumental balance. Support reciprocity is the fourth sub-scale and investigates the extent to which an individual believes there is reciprocity of support between him and the identified support network. Perceived network conflict examines the extent to which an individual believes conflict exists between him and members of the support network identified in the first part of the PSNI. The sixth sub-scale, perceived multi-dimensionality, investigates the types of support provided by each network member (Orritt et al., 1985).

The 6 sub-scale scores for each identified network member are added to get a total sub-scale score and then divided by the number of network members to get mean sub-scale scores. The total instrument score is calculated by adding the mean sub-scale scores together (Anderson, 1993).

This measure was chosen for the proposed study, as the PSNI collects data specifically related to social relationships and networks. It also assesses the 4 dimensions of social support (network structure, type of support, source of support and evaluation of support) as defined in the literature. This allows the researcher to make more specific conclusions about social support versus quality of life among young adults with and without Asperger Syndrome. Also, the PSNI was validated with a similar age group as the sample of this study.

Two studies were conducted to generate reliability and validity estimates on the PSNI using college students and counselling centre clients (Oritt et al., 1985). The authors hypothesized that PSNI total and subscale score test-retest reliabilities and internal consistency estimates for the PSNI would exceed .70. For validity, the authors estimated the construct and convergent validity would be satisfactory if correlation coefficients between the PSNI and the convergent and construct validity instruments fell within the range of .30 to .50. The results of these 2 studies revealed the following: test-retest reliability of the total PSNI score was .88 while sub-scale scores ranged from .72 to .87. Internal consistency was moderate (Cronbach's alpha =. 60) but increased (up to .77) when perceived network size was removed from the estimate. Construct validity ranged from .21 to .57. Convergent validity varied from -.25 to .20. Discriminant validity estimates varied from -.11 to .19 (Orritt et al.).

According to McDowell and Newell (1996), none of the currently available social support scales is clearly superior to others mainly because they were all comparatively new and few have been widely tested. Most measures reported similar psychometric characteristics to the PSNI. The reading level of the PSNI with Flesch-

Kincaid Grade equalled 8.9 and the readability is 57.4. The instructions for the PSNI were simplified reducing the reading level to 8.5.

Semi-structured interview

Koning and Magill-Evans (2001a) found that the students with Asperger Syndrome rated themselves higher than their parents and teachers with regards to their social skills unlike their typically developing controls. This finding was supported by a study conducted by Barnhill, Griswold, Hagiwara, Myles and Simpson (2001). These findings led to questions about the reliability of self-report for persons with Asperger Syndrome on questionnaires, especially in regards to social functioning. Using a semi-structured interview format ensured that complete information was obtained through the use of probes. This increased the reliability and validity of the data.

The interview used in the study was developed specifically for this study. Questions were used to collect data on the following variables (1) level of independence which included education, employment history, living arrangements, and mobility, (2) environment which included questions regarding leisure and (3) the social relationships which included questions regarding friends and dating. Some of this information such as income might be viewed as a more objective measure of quality of life. For more details about the interview and the coding of the variables assessed during the interview, see Appendix E. Before starting the interviews, the interviewer attended workshops related to interviewing and tested the interview out on volunteers in order to become familiar with the format and to ensure clarity of the questions. The semi-structured interview was pilot tested on volunteers from the same age range; one with schizophrenia that was originally misdiagnosed as having Asperger Syndrome and 4 without Asperger Syndrome. The wording, the acceptability, and the clarity of the questions as well as the length of the interview were investigated and changes have been made accordingly.

The interviews were scheduled at a time and place most convenient for each participant. Most of the participants were interviewed in their homes, though, some preferred to do the interview in a private room at the University of Alberta. Only these two locations (home or the same room at the university) were allowed to ensure consistency of setting when interviewing. Interview length lasted from 30 to 130 minutes. As some of the participants were now living in areas far from the Edmonton region (e.g., Northwest Territories), tape-recorded phone interviews were done with 4 young men in the clinical and 2 in the control group.

The investigator was blind to diagnosis prior to the interview but given the fact that the investigator understood the diagnosis of Asperger Syndrome, it was difficult to remain blind to those who demonstrated these characteristics during the interview. Hence, some rater bias might have occurred. Due to the small sample size, the differences in the data collection methods (i.e. phone or face to face interview, different locations) that may have led to bias could not be examined statistically. To limit the effects of bias, all the interviews were tape-recorded to allow for testing rater reliability. A research assistant who was unfamiliar with Asperger Syndrome randomly rated 16% of the recordings of both face to face and phone interviews. Inter rater reliability for four interviews using double coding of the information obtained during the interviews was good, r = .97.

Dealing with missing data

As the questionnaires were received at the time the interview took place, the investigator had a chance to identify the missing data and ask the participants whether they had filled in everything they wanted to. All of the questionnaires were returned complete. Three participants out of 25 chose not to respond when the interviewer asked about the reasons why the participant had never dated.

CHAPTER THREE

RESULTS

A description of the sample characteristics is presented followed by the results related to the three hypotheses. Data were analysed using the Statistical Package for Social Sciences (version 11.0) with the alpha level set at .05. Summary statistics (e.g. percentages, frequencies, means, standard deviations and ranges) related to the data for each hypothesis was examined prior to each analysis to ensure that the assumptions of the planned analysis were met.

Study Sample

The original study sample consisted of 57 male participants, 29 of whom had a diagnosis of Asperger Syndrome. Twenty-five (43.86%) participated in the study. There were 12 participants with Asperger Syndrome and 13 in the control group. Of the remaining 32, 1 (1.75%) was not able to participate due to a serious motor vehicle accident, 6 (10.53%) refused, 2 (3.51%) were unreachable and 23 (40.35%) were untraceable. Those in the unreachable category had a correct contact address but could not be contacted during the time of the data collection. The participants for whom no correct new address could be found were categorized as untraceable.

Because a large proportion of the sample could not be located, participants were compared to non-participants to see if there were any systematic differences for socio-economic status, age, and scores on the WISC III vocabulary subtest (Weschler, 1991) that was used as an estimate of IQ in the earlier study. Socioeconomic status, as measured by the Socioeconomic Index for Occupations in Canada (Blishen et al., 1987), did not differ, $F(1, 49) = .302$, $p = .59$), and neither did age, $F(1, 57) = 3.02$, $p = .09$. There were no differences between the participants and the non-participants on the

WISC III vocabulary scores, F (1, 55) = .16, p = .69. Participants with Asperger Syndrome did not have significantly different scores from non-participants with Asperger Syndrome on the 27-item Asperger's Syndrome Screening Questionnaire (AASQ: Ehlers & Gillberg, 1993), F (1, 25) = .33, p = .57. ASSQ scores for the participants in this study ranged from 28 to 42 out of a possible 54 (mean = 34.00, SD = 4.58) and from 20 to 51 for the non-participants in the Asperger Syndrome group (mean = 35.41, SD = 7.67). Thus, the current sample is representative of those who were in the original study.

Socio-demographic Characteristics of the Sample

The mean age of the participants at the time of the data collection was 20.33 years (SD = 1.27 years, range = 18.08 - 22.10 years) for those with Asperger Syndrome and 20.51 years for the control group (SD = 1.32 years, range = 19.01 - 24.01 years).

Overall, 64% of the sample lived in urban settings (population of community greater than 30,000) while 36% lived in rural settings (population of community less than 30,000). The majority of the participants were White (90%) as determined during the interview via observation.

Quality of life (Hypothesis 1)

The means and standard deviations for the data are presented in Table 1. The group with Asperger Syndrome appeared to be more variable in the physical domain (SD = 14.98) than the control group (SD = 6.20). As equality of variance between groups is an assumption for an analysis of variance (ANOVA), the physical domain was not included in the initial analysis. A multivariate analysis of variance (MANOVA) with four dependent variables was conducted to determine whether the quality of life scores were significantly different between groups, Hotelling's T = .81, F (4, 20) = 4.04, p = .02, effect size = .45, power = .83. This analysis confirmed that young adults diagnosed with Asperger Syndrome rated their quality of life lower than young adults without Asperger Syndrome matched on age and gender.

The univariate analyses associated with the MANOVA for the overall quality of life item and for each of the domains of the WHOQOL-BREF were examined to determine the source of the differences. Compared to the control group, persons with Asperger Syndrome had significantly lower scores for the social domain, F (1, 23) = 12.22, p = .002, effect size = .35, power = .92. There were no significant differences for the overall quality of life item, F (1, 23) = 2.52, p = .13; psychological domain, F (1, 23) = 2.57, p =. 12; and environmental domain, F (1, 23) = 1.04, p =. 32. The power was low, ranging from .17 for the environmental domain to .33 for the psychological domain and the quality of life item. There were significant differences for the social domain but scores on overall quality of life and the psychological domain were not significantly lower for the group with Asperger Syndrome.

The physical domain was examined using a t-test. Levene's test for equality of variances was significant, p =. 02. The t-test for unequal variances found that persons in the group with Asperger Syndrome had significantly lower scores than those in the control group, t (1, 23) = 3.18, p =. 006. The effect size as calculated using the d statistic equals 1.33.

In comparison to the population norms for the Australian WHOQOL-BREF domains and global items, the group with Asperger Syndrome was consistently lower (see Table 1). These differences were not tested statistically. Despite the fact that the control group consists of only 13 participants, the means for the 4 domains and the general quality of life item are remarkably similar to the Australian norms.

***Table 1.* Descriptive statistics on quality of life**

	Clinical group			Control Group			Population Norms		
	M	(SD)	Range	M	(SD)	Range	M	(SD)	Range
QOL	3.7	(0.7)	3 - 5	4.1	(0.6)	3 - 5	4.3	(0.8)	1 - 5
Physical	65.4	(15.0)	44 - 88	80.2	(6.2)	69 - 94	80.0	(17.1)	4 - 100
Psychological	61.0	(13.4)	44 - 88	69.8	(13.9)	44 - 88	72.6	(14.2)	21 - 100
Social	49.5	(23.0)	0 - 75	78.4	(18.2)	31 - 100	72.2	(18.5)	8 - 100
Environment	67.4	(11.3)	50 - 88	71.7	(9.6)	44 - 81	74.8	(13.7)	25 - 100

Perceived Social Network Inventory (Hypothesis 2)

The means and standard deviations related to social network are presented in Table 2. The total PSNI scores, obtained by adding the mean subscale scores, were examined first to determine if there were differences between groups. An independent t-test for equal variances (Levene's test, p = .15) found that persons with Asperger Syndrome were not significantly different from those in the control group on their perceptions of social support, t (1, 23) = 1.16, p =. 27, effect size = .52. Therefore, an analysis of differences on the subscales was not done and the scores appear to be similar.

***Table 2.* Descriptive statistics for scores on the PSNI**

	Clinical group			Control group		
	M	SD	Range	M	SD	Range
Total score PSNI	26.2	9.5	0 - 38.8	29.5	3.3	24.1 - 34.8
Initiation	4.1	1.9	0 - 7.0	4.9	2.19	3.3 - 11.6
Availability	5.0	1.9	0 - 7.0	6.1	1.0	4.1 - 7.0
Satisfaction	5.1	1.8	0 - 7.0	5.6	0.9	4.2 - 6.6
Multidimensionality	3.9	1.8	0 - 7.0	4.5	1.1	2.2 - 6.6
Reciprocity	2.7	1.6	0 - 5.2	3.1	0.8	2.0 - 4.4
Conflict	5.3	1.8	0 - 6.5	5.9	0.7	4.5 - 6.8

Table 3 summarizes the network composition characteristics reported by the young adults. The composition of the networks is remarkably similar except for co-workers and professionals. For those with Asperger Syndrome, as many as 2 professionals were included in their support network while the control group did not report any professionals within their networks. It is not surprising that the number of co-workers appears lower for those with Asperger Syndrome than for the control group as fewer persons with Asperger Syndrome were working (discussed in a later section).

***Table 3.* Descriptive statistics for the network composition on the PSNI**

	Clinical group			Control group		
	M	SD	Range	M	SD	Range
Family	2.4	1.5	0 - 5	2.5	1.5	1 - 5
Friends	2.4	2.5	0 - 8	3.2	2.4	1 - 9
Co-workers	0.2	0.6	0 - 2	0.8	1.1	0 - 3
Professionals	0.4	0.7	0 - 2	0.0	0.0	0.0
Religious leader	0.2	0.4	0 - 1	0.0	0.0	0.0
Self-help group	0.0	0.0	0.0	0.0	0.0	0.0

Another aspect of social support relates to having a partner. At the time of the data collection, only 2 (16.7%) young adults with Asperger Syndrome were dating compared to 6 persons (46.2%) in the control group. A two-sample chi-square test was not significant, χ^2 (N = 25) = 2.50, p =. 114.

A correlation coefficient was computed among the total PSNI scores and the overall quality of life item as measured by the WHOQOL-BREF. There was a moderate, positive correlation of .54, p = .005. This result suggests that viewing one's social network as supportive is associated with greater overall quality of life. Because the social domain of the WHOQOL-BREF would also be expected to be associated with perceived social support, this correlation was also examined. Surprisingly, there was no significant correlation between the social domain and PSNI total scores, r = .03. There was a positive moderate correlation of .40, p= .05, between the PSNI total scores and the psychological domain of the WHOQOL-BREF. This suggests that viewing one's social network as supportive is associated with greater psychological health.

Trends Related to Independence, Friends and Dating, and Leisure activities

Independence

Independence was measured in this study by examining variables related to education, employment, income, living arrangements, and mobility. During an interview, descriptive information was collected related to each of these areas, and later coded.

Education

Table 4 includes the current status and level of education completed as reported by the young adults. In both groups there were individuals pursuing post-secondary education and individuals that had not completed high school even in a modified program. The group with Asperger Syndrome seemed to have a more variable course in junior and high school compared to those in the control group. Two young adults with Asperger Syndrome finished Grade 12 but did not have enough credits to graduate. Most young adults with Asperger Syndrome revealed that during junior high and high school, they experienced significant academic problems, which were often related to social and communication deficits. With suitable support, most of them were able to be successful in school. This finding is similar to previous research (Myles & Simpson, 2002). One third of those with Asperger Syndrome were neither working nor going to school unlike any of the young adults without Asperger Syndrome.

***Table 4.* Variables related to productivity**

	Clinical group		Control group	
	N	%	N	%
Current status				
University	2	16.7	3	23.1
College	0	0.0	2	15.4
High School	1	8.3	0	0.0
Work	5	41.7	8	61.5
Not working or studying	4	33.3	0	0.0
Level of education completed				
College diploma	0	0.0	3	23.1
High school diploma	7	58.3	8	61.5
Finished grade 12 (not enough credits)	2	16.7	0	0.0
Junior High	3	25.0	2	15.4

Employment

Most (85%) of the young adults without Asperger Syndrome were employed compared to half of those with Asperger Syndrome (see Table 5). Two individuals with Asperger Syndrome had never had a paid job. Two young adults in each group were not working, as they were university students. Three persons in the control group were studying and working, as was one person with Asperger Syndrome.

Employment was classified into 5 categories based on the Four-Factor Index of Social Status (Hollingshead, 1975) (see Table 5). The one person in the semi professional group was a lab analyst. Skilled manual workers included persons working in oil exploration, engine repair, and other such jobs. The semiskilled workers and machine operators included jobs such as truck drivers and counter clerks. The unskilled workers included employees in food service and security.

Overall, in both groups, for those working, the type of employment was similar. Young adults with Asperger Syndrome were working at jobs with less social demands (meaning that no team skills were required as the tasks could be done primarily solitary) than were the control group.

***Table 5.* Variables related to employment**

	Clinical group		Control group	
	N	%	N	%
Employment				
Employed	6*	50.0	11	84.6
Not currently employed	4	33.3	2	15.4
Never been employed	2	16.7	0	0.0
Type of current employment				
Semi-professionals	0	0.0	1	7.7
Clerical and sales	0	0.0	2	15.4
Skilled manual workers	2	16.7	3	23.1
Machine operators/semiskilled	2	16.7	2	15.4
Unskilled workers	2	16.7	3	23.1
Unemployed	6	50.0	2	15.4
Number of hours worked per week				
Full-time (37 hours and more)	3	25.0	9	69.2
Part-time (36 hours and less)	3	25.0	2	15.4
None	6	50.0	2	15.4

*One person in this group was classified as studying in Table 4, accounting for the apparent disparity between the tables.

Income

Young adults with Asperger Syndrome earned less per month than did those in the control group. Table 6 reports average income. All but one individual with

Asperger Syndrome (91.7%) and 69% of those in the control group had incomes below $1530 per month, the Canadian Low-Income Cut-Off (LICOs) (Statistics Canada, 2001). Two persons with Asperger Syndrome received the Alberta Assured Income for the Severely Handicapped (AISH), which is less than $850 per month (one was living on his own).

As most young adults paid relatively little rent while living with their parents, using the LICO was not appropriate as parents were covering many costs for their child (e.g. phone, cable, electricity). For 3 young adults with Asperger Syndrome and 4 in the control group, the LICO were appropriate as they lived by themselves and were responsible for all expenses. Of the three people with Asperger Syndrome living on their own, only one worked. The other two had income from a trust fund or received AISH ($615 and $835). More young adults with Asperger Syndrome were not paying rent while living with their parents. Overall, young adults with Asperger Syndrome had less income compared to young adults matched on age and gender.

Table 6. **Distribution of variables related to income**

	Clinical group		Control group	
	N	%	N	%
Monthly average income				
Less $ 999	8	66.7	4	30.8
Between $ 1000 - $ 1529 $	3	25.0	5	38.5
Between $ 1530 - $ 2999	0	0.0	3	23.1
More than $ 3000	1	8.3	1	7.7

Living arrangements

The living arrangements of persons with Asperger Syndrome and persons in the control group were remarkably similar (see Table 7). A high proportion of the young adults in both groups lived with family members. Statistics Canada reported that 41% of persons ages 20-29 were living at home. The proportion in this sample is even higher though the age range for both groups was not as wide (ranging from 18 to 24 years of age). One third of the control group lived with friends, by themselves or with a partner while this was only the case for 25 % of those with Asperger Syndrome. Four young adults with Asperger Syndrome (33.3 %) indicated that they weren't able yet to live independently as they couldn't handle all the tasks needed such as cooking, doing laundry, or managing finances, while this was not the case for the control group.

Table 7. **Distribution of variables related to living arrangements**

	Clinical group		Control group	
	N	%	N	%
Living arrangements				
Living by himself	1	8.3	1	7.7
With partner	0	0.0	1	7.7
Friends/ roommates	2	16.7	3	23.1
Family	9	75.0	8	61.5
Independence (able to cook, do laundry, handle finances…)				
Independent	8	66.7	13	100.0
Not able to	4	33.3	0	0.0

Mobility

Surprisingly, at the time of the data collection, 41.7 % of the young adults with Asperger Syndrome were not planning to get their driver's license in the near future unlike those in the control group (see Table 8). These five individuals were not confident in their ability to drive safely. Attention problems, coordination problems and being afraid of taking the responsibility of having "a 2500 pounds piece of metal in their hands" were reasons identified for deciding not to get their license at all.

***Table 8.* Distribution of variables related to mobility**

	Clinical group		Control group	
	N	%	N	%
Mobility				
Drive own vehicle	3	25.0	8	61.5
Drive other vehicle	2	16.7	2	15.4
Public transport	7	58.3	3	23.1
Drivers license				
Has driver's license	5	41.7	9	69.2
In training	2	16.7	4	30.8
Never planning to get it	5	41.7	0	0.0

Friends and Dating

As noted earlier, there were differences between groups related to dating (Table 9). Half of the individuals with Asperger Syndrome had never dated while this was the case for only 15.4% for the control group. Social problems were the main reason cited for lack of success in developing intimate relationships. One young adult in the control group had become a parent at the age of 19. There did not seem to be differences in the number of close friends reported.

***Table 9.* Distribution of variables related to friends and dating**

	Clinical group		Control group	
	N	%	N	%
Number of close friends				
None	2	16.7	1	7.7
Between 1-3	5	41.7	5	38.5
Between 4-6	3	25.0	5	38.5
More then 7	2	16.6	2	15.4
Dating				
Yes	2	16.7	6	46.2
Not currently	4	33.3	5	38.5
Never	6	50.0	2	15.4

Leisure Activities

In regard to participation in organizations or volunteer groups, the groups were very similar. On average, young adults with Asperger Syndrome spend more time per week on leisure when compared to those without Asperger Syndrome, which is not surprising given the differences in rates of employment. Those with Asperger Syndrome reported preferring to spend more time independently. Overall, individuals with Asperger Syndrome primarily spend their time watching TV and movies, surfing on the Internet, playing video games and reading. Two of them liked writing articles and fantasy stories on the Internet. Sports wise, there was a preference for biking. Those without Asperger Syndrome liked playing a variety of sports such as soccer, basketball, skiing, riding the motorbike and going the gym. A few enjoyed outdoor recreation such as camping and fishing. Both groups enjoyed watching movies and playing video games but those with Asperger Syndrome spend more hours on it. Both groups enjoyed going to bars and spending time with their friends, though those in the control group seemed to have more chances for pursuing this leisure activity. Table 10 summarizes the numbers and the percentages regarding the variables related to leisure.

In sum, both groups were quite similar regarding the domain of independence (e.g., education, living arrangements), their social relationships such as friends, and their leisure activities. Employment and income did appear to differ though these differences were not tested statistically. Young adults with Asperger Syndrome had higher unemployment rates and some of them seemed to struggle to keep a job. As well, the young adults with Asperger Syndrome earned less per month. Young adults with Asperger Syndrome identified having problems with mobility, specifically related to getting a driver's license. Regarding social relationships, more young adults with Asperger Syndrome seemed to struggle with developing and maintaining intimate relationships compared to those in the control group.

Table 10. **Distribution of variables related to leisure activities**

	Clinical group		Control group	
	N	%	N	%
Kind of leisure preference				
Primarily social activities	1	8.3	10	76.9
Mixed	4	33.3	1	7.7
Primarily solitary activities	7	58.3	2	15.4
Number of hours spent on leisure				
Less than 20 h	3	24.9	5	38.5
Between 21-40 h	3	24.9	7	53.9
More than 41 h	6	49.8	1	7.7
Leisure time spent with				
Primarily with friends/family	0	0.0	11	84.6
Mixed	6	50.0	0	0.0
Primarily alone	6	50.0	2	15.4
Participation in volunteer group				
Yes	3	25.0	1	7.7
Previously but not current	5	41.7	7	53.8
Never	4	33.3	5	38.5
Level of participation				
Very active	5	41.7	4	30.8
Fairly active	2	16.7	3	23.1
Not active	5	41.7	6	46.2

CHAPTER FOUR

DISCUSSION

The discussion is organized under each of the hypotheses and includes considerations of how these findings add to the general understanding of quality of life of young adults with and without Asperger Syndrome. The findings of the current study are placed within the context of existing research and literature. As well, areas for further research, the limitations of the current study, and the relevance for clinical practice are addressed.

Quality of Life (Hypothesis 1)

Young adult men with Asperger Syndrome do report a significantly different quality of life than do young men without Asperger Syndrome. Their scores were significantly lower on the social and physical domains but not on the single overall quality of life item.

Social domain

Given the nature of Asperger Syndrome, which is characterized by impairments in social interaction such as developmentally inappropriate social skills and limited ability to take part in reciprocal communication (Barnhill, 2001), it is not surprising that these young adults were less satisfied with their social relationships compared to those without Asperger Syndrome. This difference in scores was clinically as well as statistically significant as the young adults with Asperger Syndrome scored markedly lower than the control group and the Australian normative sample. Clearly, these young adults are aware of their social skills deficits and perceive it as having an impact on their quality of life. In examining the items in this domain, it appeared that the differences between groups were particularly marked on two of the items, sexual activity and social support from friends.

Related to sexuality, Nordin and Gillberg (1998) argue that the growth of sexual drive is not accompanied by a corresponding growth in social 'know-how' which may lead to embarrassing situations when young adults with Asperger Syndrome attempt to initiate intimate relationships. This is supported by anecdotal information from one of the participants. This young man indicated that it was hard for him to 'have a girlfriend' as he never knew which behaviour was appropriate leading him to do "things that you only do once you date already". He did not specify the behaviour to which he was referring. In general, results of the interviews indicated that a lack of necessary skills, regardless of their strong desire to do so, was the most common reason these young men gave for being unable to establish intimate relationships, similar to the findings of others (Nordin & Gillberg; Tantam, 1991).

Out of the 12 individuals with Asperger Syndrome in this study, half of them had never dated compared to only 15% of those in the control group. Although those with Asperger Syndrome reported dating less than did those without Asperger Syndrome, it was still more frequently than reported by those in a study by Szatmari and colleagues (1989). They found that, of 16 young Canadian adults (mean age= 26 years, range 17-34) diagnosed with Asperger Syndrome or higher functioning autism, 1 was married and only 3 had dating experiences. Although none of the young men with Asperger Syndrome in our sample were married, 2 were dating and 4 had been dating before. The difference in results may be due to differences in the diagnostic categories used in the two studies. The sample studied here was limited to only individuals with Asperger Syndrome while persons with higher functioning autism, who may have more severe impairments in social relationships and communication, were included in the Szatmari et al. study. Also, their sample was assessed in the 1950s and 1960s, well before consensus was reached on diagnostic criteria, and the data regarding dating came from the parents. No information was obtained as to how exactly they measured dating, e.g., frequency in the last year, and duration of relationships. Despite the methodological differences between the two studies, the more positive findings in this study may indicate that more attention has been focused on social rules and the context of sexual expression in the years since the Szatmari et al. study so that more of these young men have a greater chance to successfully initiate intimate relationships. It is encouraging to see that regardless of the social problems associated with the syndrome, at least half of the young men had been or were dating. Some of the young men in the current study had been receiving social skills intervention at the time of the initial study. Continued efforts in this area are clearly still needed.

Satisfaction with support received from friends was also an item on the social domain. Differences on this item could be expected as young adults with Asperger Syndrome lack the appropriate social skills needed to establish and maintain friendship relationships that are supportive. This quality of life related item differs from the question used to look at the number of friends during the structured interview on which there were few differences between groups. The difference lies in the support aspect of the friendship item on the quality of life scale. One individual with Asperger Syndrome confirmed this by saying that he has a few good friends but none that he would phone in the middle of the night when he feels lonely.

Several authors have addressed the relationship between social support and social competence (Anderson et al., 1998; Dunkel-Schetter, Folkman & Lazarus, 1987;

Hansson, Jones & Fletcher, 1990; Heller, 1979). According to Basham, Hacker, Sarason and Sarason (1985) persons with high social support were rated by others as more attractive, interesting and socially competent than persons low in support. They operationalized social competence as communication skills (e.g. eye contact, duration of speech, voice quality) and interpersonal style (e.g., assertiveness-submissiveness, relevant-irrelevant contributions and gesturing). Moreover, Clark, Cohen and Sherrod (1986) found that social competence, defined as assertive skills, dating skills and same-gender communication skills, predicted social support and friendship formation and were stress protective among college-aged adults. As social competence refers to the skills and strategies that allow close emotion-based relationships and productive collaboration with groups, it is not surprising that the satisfaction with social support received from friends might be lower for persons with Asperger Syndrome who are less able to develop social competence (Gutstein & Whitney, 2002). Howlin and Goode (2000) reported that the inability to develop social competence could be the leading factor in the failure of most adults with Asperger Syndrome to attain even a minimal level of quality of life in their lives as social competence has been repeatedly demonstrated to be a critical variable in predicting success in future life (Denham et al., 2001).

In addition, Myles and Simpson (2001) argue that those with Asperger Syndrome do not acquire greater social awareness and skills merely as a function of age. Rather, to succeed in social settings, they are required to use increasingly sophisticated social skills and to interpret ever more subtle social nuances as they progress through school and adult life. Hence, they may find themselves at more and more variance from prevailing social norms as they move through adolescence and adulthood leading to dissatisfaction with their sexual life and the support received from friends. The same may not be true for support received from family members who have other reasons for maintaining a relationship than do friends. To conclude, even though those with Asperger Syndrome have a desire to develop and maintain supportive friendship relationships, their overall social skills seem to be insufficient to allow them to fulfill this desire.

Physical domain

Surprisingly, young adults with Asperger Syndrome were less satisfied with their physical health compared to those without Asperger Syndrome. This result was clinically as well as statistically significant. The physical domain addressed items such as pain and discomfort, dependence on medical treatment, activities of daily living, work capacity, energy and fatigue, mobility, sleep and rest. Two possible explanations for this result related to the impairments associated with Asperger Syndrome were examined: 1) clumsiness of movements, which is a common feature of Asperger Syndrome (APA, 2000), may have a greater influence on perceptions of physical health than currently thought, and 2) sensory hypersensitivity, which is common in individuals with Asperger Syndrome (Alisanki et al. 2000; Dunn, Myles & Orr; 2002), may have an impact on physical health. In addition, the literature related to persons with psychiatric disorders was examined briefly to determine how unique this finding was and to determine if there were other possible explanations for the result that are not unique to persons with Asperger Syndrome.

Clumsiness, which was viewed by researchers such as Butler and Ghaziuddin (1998) as a major clinical diagnostic feature in the past, might impact physical health and influence one's quality of life to a greater extent than expected. Though most researchers agree that clumsiness is common in individuals with Asperger Syndrome, reliable estimates of the prevalence of motor impairments are not available (Ghadziudden, Ghadziudden & Tsai, 1992; Gillberg, 1989; Smith, 2000; Szatmari, Bremmer & Nagy, 1989; Tantam, 1991). Furthermore, comparison between existing studies of clumsiness is difficult, particularly because consistently agreed upon criteria for the diagnosis of Asperger Syndrome do not exist (Howlin, 2000) and few studies use the same criteria (Ghazuiddin et al., 1992; Smith, 2000).

Clumsiness can be defined as an impairment of skills on standardized tests of motor functioning, below the level expected based on intelligence and in the absence of a known neurological disease (Butler & Ghaziuddin, 1998). Wing (1981) observed that children with Asperger Syndrome tended to have poor motor skills, along with coordination and balance problems. Cichetti, Klin, Rourke, Sparrow and Volkmar's (1995) study of persons with Asperger Syndrome found that 90% had deficits in fine motor skills and all participants had deficits in gross motor skills. These findings support those of Baird, Barnett, Green, Henderson and Huber (2002) who reported that young adults with Asperger Syndrome face difficulties with absence of facial expression, poor fine motor coordination and lack of fluency in locomotion.

According to Myles and Simpson (2002) the implications of such deficits are significant. First, they argue that being awkward and clumsy makes it difficult to participate successfully in games requiring motor skills. Thus, poor physical abilities and performance exacerbate their social deficits. Because participation in games and related activities is a primary social activity for students, problems in this area have an impact well beyond motor coordination. Second, fine motor difficulties may interfere with a variety of school activities, such as handwriting, art, and industrial arts (Myles and Simpson). Their findings are supported by anecdotal information collected in the interviews for this study. Many of the young adults with Asperger Syndrome apologized for their 'bad/messy' handwriting on the questionnaires and indicated that this was a major concern during high school. Some mentioned that maintaining labour-type jobs (e.g., assembly worker) was difficult due to a lack of eye-hand coordination. A few of them refused to learn how to drive, as they knew that their 'clumsiness' would influence their driving ability.

To conclude, current literature in combination with our findings show that individuals with Asperger Syndrome do have ill-coordinated movements that may have a greater impact on perceptions of physical health than anticipated.

Sensory hypersensitivity, another possible explanation for the results, might have an influence on how one perceives the environment, which in turn could influence physical health. Many individuals seem to experience some level of heightened sensory awareness; in fact, Gerland (2000) goes as far as to say that almost everybody with Asperger Syndrome has problems with some of their senses. Grandin (1995), referring primarily to those with autism, argues that problems caused by noise sensitivity, over sensitivity to touch, and difficulties with rhythm, cause many behavioural problems and influence functioning in daily living, energy levels, sleep, and the capacity to work which in turn could explain the differences in scores between groups in the current study. Our findings are supported by others who have reported the relationship between sensory processing and functions in daily life, including learning, play, work and socialization (e.g., Ayres, 1972, 1979; Cook & Dunn, 1998; Dunn, 1997, 1999).

To date, only one study has been published on the sensory characteristics of individuals with Asperger Syndrome. Dunn et al. (2002) compared the performance of

42 children with Asperger Syndrome and 42 children without disabilities to determine the sensory integration characteristics of those with Asperger Syndrome. The parents of those with Asperger Syndrome reported that their children exhibited variable patterns of performance when compared to peers without disabilities on a measure of sensory functioning. Those with Asperger Syndrome had impairments in 1) physical endurance and muscle tone, 2) oral sensory sensitivity, 3) attention (i.e., distractibility and inattention), and 4) modulation (i.e. poor ability to regulate responses to sensory stimuli). Over 75% of the individuals studied demonstrated behavioural problems when sensory issues were violated. The effects of sensory sensitivity might have influenced how participants with Asperger Syndrome in the current study responded to items such as pain and discomfort, activities of daily living, work capacity, energy and fatigue, and sleep and rest. Clearly, more work is needed to determine the extent of sensory hypersensitivity in persons with Asperger Syndrome. However, if the proportions reported so far are replicated in other studies, it is important that support services and researchers do not overlook these issues as a possible explanation for results.

The literature related to persons with psychiatric disorders indicated that persons with severe mental illness have poor physical health and increased morbidity and mortality compared to the general population (e.g., Mirza & Phelan, 2002). Although persons with Asperger Syndrome would not be described as having severe mental illness, the same processes that affect both physical and mental health in such persons may also affect them. Mirza and Phelan (2002) argue that a range of medical, social and behavioural factors are responsible for the poor physical health of mental health patients. According to Felker, Yazel and Short (1996), co-morbid medical illnesses such as cardiovascular, gastrointestinal and musculoskeletal disorders are very common in persons with severe mental illness. These medical co-morbidities appear to be under-diagnosed causing or exacerbating psychiatric symptoms, which in turn influences physical health (Delahanty, Dixon, Fisher, Lehman & Postrado, 1999). Angermeyer and colleagues (2001) found that the impact of schizophrenia on the physical health domain of quality of life was larger than expected, which could be due to the side effects of neuroleptic drugs. No information was collected as to whether the participants in this study were taking medications or if they had any health or medical conditions. One can also argue that due to problems in physical health (i.e., clumsiness, sensory hypersensitivity or other medical co-morbidities), those with Asperger Syndrome and other mental health conditions lack the motivation to participate in physical activities, which in turn could contribute to less optimal physical health.

In sum, the implications of lower perceived quality of life in the physical domain are significant. Both clumsiness and sensory hypersensitivity are possible explanations for the results in the physical domain. These areas affect sports, social skills, writing, art, industrial arts and more. Hence, investigating the extent, the severity, and the impact of clumsiness and sensory hypersensitivity would be worthwhile. However, other factors such as side effects of medication that are common in the psychiatric population also need to be explored. Information gained from these studies could provide health care professionals and parents with more concrete information as to how these issues could be addressed in future interventions so that this area of quality of life could be improved.

Psychological domain

There were no differences between groups in scores on the psychological domain even though it was hypothesized that feelings of anxiety/depression, which are particularly likely to occur in persons with Asperger Syndrome, would have a negative impact on quality of life. The lack of differences on this domain may be an accurate reflection of their perceptions. According to Gillott, Furniss and Walter (2001), anxiety may not play a fundamental role in these young adults' difficulties but may instead represent a secondary phenomenon, which results from their self-awareness of difficulties when facing situations in which they are expected to display age-appropriate social judgment and social behaviour. The anxiety might be focused on the social situations that individuals with Asperger Syndrome find difficult, resulting in perceptions of lower quality of life related to the social domain but not the psychological domain. Alternatively, the anxiety disorders that persons with Asperger Syndrome develop may be different to those of typically developing peers (Gillott et al., 2001) and might not be reflected in the type of items included in the measure used in this study.

Two other potential explanations were examined: 1) the sample was too small to detect small but important differences and 2) there was a sampling bias in both groups. First, it is possible that with a larger sample size the result for the psychological domain might be significant as the p-value was .12 and the effect size was .65. While there were differences between groups in the expected direction that were not small, the power (.30) was too low to detect differences. Research with a larger sample size might provide evidence of the negative impact that Asperger Syndrome has on the psychological domain. Second, it could be that no differences were found due to sampling bias. Although both groups were considered free of pathology other than Asperger Syndrome, this was not measured; nor were confounding factors such as family circumstances considered. Therefore, it could be that both groups in our sample might not have been representative of the general population regarding mental health. Furthermore, the young adults in the control group had lower mean scores on the psychological domain compared to the Australian norms although these differences were not tested statistically. However, those in the control group were remarkably similar to the scores of the normative sample in all other areas so support for a sampling bias in the control group is tenuous.

In summary, there were no differences on psychological health between young adults with Asperger Syndrome and the control group. Further research with a larger sample size or different measures is needed to determine the true nature and prevalence of anxiety disorders and its impact on the quality of live in persons with Asperger Syndrome compared to typically developing peers.

Conclusion

The findings regarding quality of life supported the hypothesis that Asperger Syndrome has a negative impact on the social relationship domain and, surprisingly, the physical domain of quality of life, an area not hypothesized to be affected. These findings underline the need to consider that the impact of Asperger Syndrome on quality of life is broader than currently assumed in the literature and clinical practice.

Perceived Support Network Inventory (Hypothesis 2)

Young adults with Asperger Syndrome perceived their social support, as measured by the PSNI total score, in a manner similar to that of other young adults. No differences were found in the network composition of both groups. The lack of differences on their perceived social support and network composition may be an accurate reflection of their perceptions. However, more research needs to be conducted to validate this explanation as no previous data on perceived support and network composition for those with Asperger Syndrome is available.

An alternative explanation for the lack of differences on the PSNI may be due to a lack of sensitivity of the test when used with persons with disabilities or addictions. The findings of two studies, one by Anderson and colleagues (1993) and one by Malow, McMahon and Kouzekanani (1999) who used the PSNI to measure perceived social support, are discussed as both studies reported no differences between groups on perceived social support.

Anderson and colleagues (1993), who investigated the perceived support of 26 Alberta university students with a physical disability of a similar age to the persons in the current study, found no significant differences in comparison to 66 students without physical disabilities. The total scores on the PSNI for those with physical disabilities were 28.82, slightly higher than those of persons with Asperger Syndrome in this study (26.18). The mean scores for the control groups in both studies were remarkably similar (for this study- 29.53, Anderson et al. - 29.64) indicating that the control group in this study, despite the small sample size, appears to be representative of those without disabilities. The only difference they reported was in the network composition; those with physical disabilities included more professionals compared to persons without physical disabilities, a trend noted in the current study.

Malow and colleagues (1999) also found no differences in perceived social support between completers and dropouts from a residential treatment program for cocaine abuse (average age= 27.40 years, N = 54). The mean total PSNI scores of 30.06 and 28.87 respectively were similar to those reported in this study. The variability on the total PSNI scores for the dropouts (SD = 9.60) in their study was similar to that found for those with Asperger Syndrome (SD = 9.5). No information on size of the network from the PSNI was available.

The structure of the PSNI may interact with characteristics of disorders such Asperger Syndrome where individuals interpret statements such as instructions quite literally. The measure provides 12 spaces for listing the names of persons in a social network. Although the directions stated clearly that not all the spaces needed to be completed, some persons (N= 5) with Asperger Syndrome filled in all of the spaces. Some of this information differed from that provided in the semi-structured interview where there was no indicator for a certain number of responses. It would be interesting to see whether these young adults with Asperger Syndrome would complete the PSNI differently using a different format.

To summarize, at least three studies using different populations have failed to detect differences between groups. It may well be that there are truly no differences in social support between these groups or it may be that the manner in which social support was measured did not detect differences.

Another possible explanation for the lack of differences between groups may relate to the small sample sizes. The authors of the PSNI did find significant differences between a sample of 174 undergraduate students who were taking an introductory psychology course and received credits for participation and 28 clients from a university counselling centre (Oritt et al., 1985). The means for the total PSNI score were 30.39 (SD = 3.60) for the student group and 27.35 (SD = 3.57) for the client group and quite similar to those reported in the studies of young adults discussed above. Their total sample size was larger than any of the other studies reviewed here and thus they may have had more power to detect differences. In the current study, power was estimated as only .23. However, further research on the discriminant validity of the PSNI is needed to ensure that the PSNI is indeed sensitive to important differences. Such evidence would help in determining if the lack of differences between groups found in this study was valid and not a product of sample size or the measurement tool used.

Trends Related to Independence, Social Relationships and Environment

The main finding related to this research question is that most young adults with Asperger Syndrome seemed to be very similar to other young adults on the following aspects of quality of life as measured during the semi-structured interview: 1) independence which included education, employment, income, living arrangements and mobility; 2) social relationships such as friends and dating; and 3) leisure activities. The most important findings are discussed here.

Independence domain

Education: Hans Asperger described the academic performance of his patients as uneven (Barnhill et al., 2001). Indeed, those with Asperger Syndrome in this study had a more variable course in junior high and high school, although the educational achievements were quite similar for both groups. According to those with Asperger Syndrome, this variable course during school was because they experienced significant academic problems that were often related to social and communication deficits. During the interviews, a few young adults reported being aware that they were different from their peers resulting in problems with self-esteem and self-concept though most reported that this improved with age. Myles and Simpson (2001) concluded that children and youth with Asperger Syndrome are relatively easy targets for teasing and bullying by others, and indeed, a few in this study mentioned being teased. Luckily, most of the young men with Asperger Syndrome noted that they felt happier and less stressed once they finished or quit high school and began working or pursuing post secondary education.

Employment: Despite the fact that all but three of the young men with Asperger Syndrome were educated in mainstream settings and completed high school, their employment rates were disappointing. Half of them were employed compared to most (85%) of the young adults without Asperger Syndrome. Two of them never had a paid job. Their employment rate was very low compared to statistics for adult males in Alberta where only 4.7% were unemployed (Statistics Canada, 2001). According to Gutstein and Whitney (2002), studies of adults with Asperger Syndrome have found that they are likely to be unemployed or underemployed. Howlin and Mawhood (1999) also reported that, despite the potential to work, few young adults were in regular employment. Even among those with formal qualifications, employment levels were disappointing and occupational status was low. More recently, a study conducted by Bernard, Harvey, Potter and Prior (2001) found that only 12% of the adults within the autism spectrum disorders were engaged in full time employment. Social difficulties in the workplace were reported as the leading cause of job failure.

Persons with Asperger Syndrome are, of course, not alone in experiencing difficulties with employment. For individuals with any form of disability the chances of finding or keeping employment in the open work market are extremely limited (Goode & Mawhood, 1999). Indeed, rates of unemployment for young people with disabilities are staggeringly high. Those with 'moderate' disabilities had an unemployment rate of over 55% and almost 75% of those with a 'severe' disability were unemployed (Statistics Canada, 1995). Given this background, the employment rate of persons with

Asperger Syndrome in this study is better than that reported in the literature for such groups and similar to those with moderate disabilities in Canada. Overall, for those working, the type of employment was similar although those with Asperger Syndrome were working at jobs requiring less social demands.

Living arrangements: A high proportion of both groups still lived with their parents and living arrangements of those with and without Asperger Syndrome were similar. Four persons with Asperger Syndrome described themselves as not yet able to live independently. Two persons with Asperger Syndrome were actually living independently, an encouraging result.

Environmental domain: Leisure Activities

In regards to leisure pursuits, both groups were very similar. Those with Asperger Syndrome spend more time on leisure, which is not surprising given the differences in rates of employment. A study of the adult outcomes conducted by Bernard and colleagues (2001) reported that 37% of persons within the autism spectrum disorder reported no participation at all in social activities, while 50% reported going out no more than once or twice per month. This is in contrast with the findings of the study reported here. Both groups of young men were surprisingly similar in the way they spent their leisure time. Both groups participated equally in volunteer groups or organizations (66.7% of those with Asperger Syndrome compared to 61.5%) and were equally active. All young men with Asperger Syndrome mentioned that they went to bars with friends two to three times per month though those without Asperger Syndrome went almost every weekend.

Conclusion

To summarize, both groups were quite similar regarding the domain of independence (e.g. education and living arrangements), their friendships and their leisure activities. Employment and income did appear to differ though these differences were not tested statistically.

Relevance to Clinical Practice

Both families and professionals such as occupational therapists struggle to understand the nature and unique characteristics of Asperger Syndrome (Myles & Simpson, 2002). Indeed, many unanswered basic questions related to the nature and characteristics of Asperger Syndrome daily confront parents and professionals who must diagnose, teach, raise and otherwise support children and youth with the syndrome. At the same time, there is an ever increasing flow of information related to accommodations, supports, methods and interventions that can help to meet the needs of these individuals (Myles & Simpson). As the syndrome is a very complex disorder, there is every indication, according to researchers (Bock, 2001; Myles & Simpson; Williams, 2001) that needs are best addressed through a variety of methods used in an individualized manner. For this reason, the recognition of the impact of the consequences of Asperger Syndrome on the client's quality of life needs to be considered, especially as those individuals have to live without expectations of being cured. Hence, quality of life assessments should be more valued tools within occupational therapy practice. This more 'consumer oriented' approach to service delivery reflects the perception that the clients' own opinion of what is happening to them is important and provides important feedback to service providers as to how to be more client centered within their practices. The areas for which the findings of this study have the most relevance for clinical practice relate to the social and physical domain.

The findings have implications when addressing the social aspects of the person. Not surprisingly, interventions should continue to focus on improving the social skills of those with Asperger Syndrome so that they are better able to develop and maintain satisfactory support relationships with peers. Social skills groups, role-playing and videotaped feedback followed by systematic training may be useful when trying to teach persons with Asperger Syndrome the requirements of social interaction and conversation (Tantam, 1991). Furthermore, occupational therapists should recognize that sexual education and relationships are essential for those with Asperger Syndrome as the findings related to the social domain of the quality of life measure suggested that they were not satisfied with their sexual life. Many young adults with Asperger Syndrome may have missed out on sexual education at school when they were growing up as this has only been more recently included as a compulsory subject in the national curriculum (Aylott, 2000). Even if they did receive 'sex education' it may not have been provided within a 'social skills context' which is designed to ensure young people understand the social context for sexual expressions and behaviour. Hence, social skills training interventions should focus not only on understanding the social rules and context of sexual expression but should allow these young adults with Asperger Syndrome to learn more about themselves. This is particularly important as scholars argue that these young adult's social deficits will never totally disappear (Alisanski et al., 2001; Tantam, 1991). Professionals need to try to minimize the impact of these deficits on quality of life by helping them to succeed in social settings such as dating which require the use of increasingly sophisticated social skills and interpretation of ever more subtle social nuances. Additionally, the goals of social skills interventions must shift from survival-oriented behaviours to more sophisticated abilities so that those with Asperger Syndrome will be better able to share feelings and ideas with their social partners leading to more satisfying, supportive and intimate relationships (Gutstein & Whitney, 2002).

The findings also have relevance when addressing physical aspects of the person. They underscore the need to consider physical health, and possibly sensory issues and clumsiness, when conducting a functional analysis of behaviour of those with Asperger Syndrome. Too often persons are seen in mental health types of settings where the focus of interventions is more on the social or psychological aspects of the person with little regard for the physical aspects. In addition, accurately assessing motor skills and sensory issues could help occupational therapists to develop interventions related to appropriate jobs as Howlin and Mawhood (1999) have indicated that careful job placements for those affected by Asperger Syndrome is one of the key elements associated with successful employment. Obtaining detailed information on their level of functioning, their past educational and job history, motivation, preferences and motor skills will lead to more successful searches for jobs which are better suited to the abilities of the specific individual. When suitable jobs are identified and the clients started their jobs, continuing guidance and support, especially in the beginning, is needed to ensure that the clients can cope with all the social and occupational requirements of the job (Goode & Mawhood, 1999). One young adult indicated that he sometimes badly wanted his employer to see how hard it was for him to do this kind of work. He continued that "it would help if some professionals could spend some of their time educating and informing potential and existing employers and advising colleagues on how to deal with or avoid problems" leading to less stress in the workplace resulting in better performances.

Clinicians also need to remember that some of the findings such as education, living arrangements and leisure pursuits are surprisingly positive. Social support does not appear to be an area on which to focus as both groups were equally satisfied with the support received from their social networks. Other than employment and income, those with Asperger Syndrome seem to do quite well compared to those not affected by Asperger Syndrome. The results do indicate that the bleak prognosis often given to parents of young children with Asperger Syndrome may not be warranted. As well, these positive findings encourage a focus away from the individual and his impairments and onto exploring how the environment can alleviate barriers in the social and physical domain. Occupational therapists could do this by helping families and persons with Asperger Syndrome advocate for their rights and to have needs addressed. Increasing the public awareness of Asperger Syndrome and other disabilities is a task for the whole society and should be the subject of political decision-making and initiation of effective programs. Data from quality of life measures could be used in the future to lobby for sufficient resources or to inform health and social policy.

In conclusion, the results of this study demonstrate that the reduction of the negative impacts of Asperger Syndrome on quality of life, whether physical or social, cannot be addressed by medical or psychosocial services alone but requires intervention within a holistic model of practice that includes all aspects of one's life. Quality of life assessments can be used to prioritise problems, facilitate communication, screen for potential problems and monitor changes or response to treatment. A disability like

Asperger Syndrome affects and is affected by many aspects of people's lives, such as their relationships with friends, satisfaction with their sexual life, and information about these aspects should influence treatment decisions and assessments of health care need. Using quality of life measures in clinical practice will help ensure that treatment focuses on the client rather than the disability.

Implications for Theory

Given the pilot nature of this study, the implications of the results for evaluation of theory must be considered as tentative at best. However, the study does raise a number of questions about the measurement and conceptualization of quality of life. Does the model of quality of life used in this study capture all the variables that are having an impact on these young men's quality of life? Does one domain have more influence on their overall quality of life than other domains? Are there sufficient items on the WHOQOL-BREF to capture the concept of quality of life? How valid is a single score on a question of overall quality of life? Is a summary score based on subscale scores across multiple domains needed to fully understand the impact of Asperger Syndrome? Further research is obviously needed to address these questions. However, the findings of this study do provide some tentative indications for future research in the area of quality of life theory.

The emphases within the WHOQOL conceptual model are on the subjective nature of quality of life and on the need to explore all aspects of life having a significant impact on quality of life (Herrman et al., 1998). The challenge lies in the uniqueness of quality of life for individuals. Thus, the WHOQOL model may not capture all the variables that have an impact on these young men as it, like many models, uses a standardized model and preselected domains which fail to take into account this 'individual uniqueness' (Bradley et al., 1996). Using a standardized measure that asks every person the same questions may not adequately measure quality of life. Even though focus groups of patients, health professionals and 'healthy' participants proposed the items in the WHOQOL model, a more individualized approach, which allows clients to define quality of life in relation to their goals and expectations, may be more appropriate. Bradley and colleagues (1996) suggest that for valid measurement of quality of life, a measure needs to evaluate each individual on the areas of life that are most important, quantify current functioning in each of these personally nominated life areas, and weight the relative importance of the areas for that individual at that particular time. The WHOQOL Group addressed this issue in developing their model by using weights derived from the general population who were asked to value the range of determinants to be included in a quality of life questionnaire. Hence, the participants' responses on the WHOQOL-BREF are valued according to these weights. However, according to Bradley and colleagues, these weights are unlikely to represent the values of the individual participants as different groups of patients could attach a range of weights to the same domains. Furthermore, the weights attached to the same domains will differ between persons, may vary with disability and culture and could change at different periods in life (Bradley et al; Carr & Higginson, 2001b). This is not addressed in the WHOQOL conceptual model as scoring of the WHOQOL-BREF involved recording the quality of life for each domain separately (profile measure) with a single index score on overall quality of life and health (Bradley et al., 1996). If there were some estimate of the relative importance of each of these domains, it would have been easier to provide meaningful interpretation of the results. For example, is the impact of

Asperger Syndrome greater on the physical or social domain or are other areas more influential that are not addressed in the WHOQOL model? To address this issue, recent literature suggests that the conceptualization of quality of life should focus on individualized measures to truly capture the uniqueness of each individual's quality of life (Carr & Higginson, 2001a, 2001b). However, this individualized way of assessing quality of life has its own problems (Carr & Higginson, 2001b) as persons who are very sick or have difficulties with attention or cognition may have difficulty understanding the system of direct weighting, and the factors that are important may change with mood and time. Most importantly because of its individualized nature, the interpretation and analysis of the data is complex, making the comparison of groups of patients, or change within individuals over time, difficult. Such an approach, while capturing individual uniqueness, would not have allowed easy comparison of the groups in this study. Indeed the questions addressed by such an approach would be quite different from those in this study. More research needs to be conducted to examine whether a true assessment of quality of life can only be achieved by using weights for individual patients without making it impossible to address research questions; which require comparison between groups and assessment of change within individuals; as those posed in this study.

Another issues related to scoring is the validity of the single item measuring overall quality of life. The results showed no differences between the 2 groups on overall quality of life item. Hence, is there such thing as overall quality of life? Or is it really domain specific? The results provide some preliminary data that quality of life can not be addressed by measuring it on one overall quality of life item but requires investigating all the areas/domains that are important in an individuals life.

In sum, two suggestions have been made as to how the WHOQOL conceptual model might be modified based on the results of this study. First, the extent to which the WHOQOL conceptual model truly reflects an individual's quality of life needs more investigation to see whether the WHOQOL-BREF is a client centered measure. Also, addressing what is important to these young men in particular, how important these domains are and how large the influence of that domain is on their quality of life would be helpful in providing meaningful interpretations of the results. Second, the validity of the responses on a single score on a question of overall quality of life does not seem to be appropriate if only one item is used. The results suggest that quality of life can best be assessed by looking at the different domains. Further research should focus on investigating whether a summary score based on subscale scores across multiple domains is needed to fully understand the impact of Asperger Syndrome.

Limitations

The results of this study should be interpreted with caution for a number of reasons. First, an obvious limitation of the study is the small sample size. This resulted in a low level of power to detect differences in areas such as the single quality of life item and the psychological domain of the WHOQOL-BREF. Unanticipated difficulties in tracing 40% of the original sample and making appointments with some others resulted in a smaller than anticipated sample size. Most families of those with Asperger Syndrome seemed to move more than those without Asperger Syndrome resulting in incorrect contact addresses. Locating them was extremely hard as many had no ongoing connections through the mental health services used to recruit them initially as they were older than 18. Vehicle registry searches could not be used, as most of them were not driving.

Second, it is unclear the extent to which the sample is representative of individuals with Asperger Syndrome in general or, in the case of the control group, of the general population of young men of this age. Those who did participate did not differ from those who did not participate or could not be located in terms of SES, age, ASSQ scores, and the estimates of verbal intelligence. However, the groups may well differ on other parameters that influence quality of life such as mental health problems and family circumstances. Although both groups were considered free of pathology other than Asperger Syndrome at the time of recruitment, pathology (e.g., depression) was not measured directly at either assessment point. The control and the clinical group in our sample may not be representative of the general population for each condition, as the representativeness of the original sample is also not known. For those with Asperger Syndrome, the original sample was representative of those with Asperger Syndrome who are seen in clinical practice, as all persons meeting the inclusion criteria and receiving intervention in the Edmonton area were included. For the control group, the fact that their scores on the quality of life measure were very similar to the normative values, indicating that they were not unlike the broader population in this area, decreases some of the concern about their representativeness. Also, their scores on the measure of social support were very similar to the control group in a number of other studies.

Third, the findings are exclusively based on the self-perceptions of these young adults. Hence, there may be some concerns about accuracy in areas such as number of friends and dating experiences. To minimize the effects of inaccuracies, probes for detailed information, such as asking the names of friends and what they did with friends on a regular basis, were used. However, this limitation still applies to responses. Future research that includes parents as well as the young adults themselves could provide more answers on questions regarding the accuracy of some of the findings.

Fourth, there was no confirmation that the persons with Asperger Syndrome continued to meet the criteria for Asperger Syndrome. However, the current understanding within the clinical and research practice is that Asperger Syndrome is a developmental disorder and the clinical picture rarely changes over the years (Barak, Holan, Meir, Ring, Stein & Weizman, 2001).

Directions for Future Research

The methods used in this study and the results suggest a number of directions for future research studies:

1) Larger studies reflecting broader geographical representation need to be conducted to verify the validity and reliability of this pilot study about quality of life.

2) More research into clumsiness and sensory hypersensitivity is badly needed, not only to identify the level of true risk, but also to improve knowledge amongst clinicians as to whether to address these areas, and if so, the appropriate intervention strategies to use. Careful systematic studies with large samples are needed to clarify the occurrence of sensory hypersensitivity or clumsiness, its presence across the lifespan, and its impact on physical quality of life. Future research could address a number of questions. What are the implications of clumsiness and/or sensory hypersensitivity on the physical health of individuals with Asperger Syndrome? Does clumsiness have more of impact on long term physical health than sensory hypersensitivity or vice versa? Does Asperger Syndrome have a differential impact on physical health, and

therefore one's quality of life, at different ages (e.g., greater impact in childhood and adolescence)? To answer these questions, long-term follow up of this sample and new research on the influence of Asperger Syndrome on physical health is needed. Long term follow-up and other research would indicate if the degree of clumsiness and/or sensory hypersensitivity is predictive of scores on the physical domain of the WHOQOL-BREF with implications for future development of service delivery and programs.

3) Qualitative methodologies need to be explored with those with Asperger Syndrome. This might help clinicians, educators and parents to further understand how these young adults define their quality of life. Would they include similar domains and facets as those addressed in the WHOQOL-BREF? If so, how would they define their physical health? Would they indicate sensory sensitivity and/or clumsiness as components having a negative impact on their quality of life? Or would they come up with other issues? Qualitative research might also provide some answers as to how these young adults with Asperger Syndrome define friendships. This information might help in providing an explanation for the discrepancy between their dissatisfaction with the social domain of their quality of life and their satisfaction with their perceived support network.

4) Secondary data analysis with the data of Koning and Magill-Evans (2001a) and the data collected in this study would be useful to determine whether some of the variables investigated six years ago would predict outcome during early adult life. More specifically, examining the relationship between the earlier ratings of social skills/social perception of the individuals with Asperger Syndrome and their quality of life would be interesting as social competence has been repeatedly demonstrated to be a critical

variable in predicting success in future life. Some scholars even argue that it could be the leading factor in failure of most adults with Asperger Syndrome to attain even a minimal level of quality of life in their lives (Denham et al., 2001; Goode & Howlin, 2000).

However, such research would need to address whose scores to use as the predictor variables. Koning and Magill-Evans (2001b) found that on average, adolescents with Asperger Syndrome rated themselves more competent on social skills than did their parents and teachers, unlike those in the comparison group. Barnhill et al. (2001) who examined the social problems and adaptive behaviour of those with Asperger Syndrome found that parents perceived their child to have significant deficits in a variety of socially related areas whereas teachers perceived the children to have not only fewer but also less significant deficits. Using the person with Asperger Syndrome's scores may be problematic as a basic characteristic of Asperger Syndrome includes a deficit in the capacity to take the perspective of others and understand one's own feelings and behaviours relative to commonly accepted social rules (Barnhill et al.). Koning and Magill-Evans found a low correlation between their ratings of social skills on a standardized measure and the scores obtained on an objective measure of social perception. Burton et al. (2000) argued that there is no direct relationship between psychological distress and awareness of disability and emotional symptomatology in the Asperger Syndrome group. Secondary data analysis with the data of Koning and Magill-Evans (2001 b) and the data collected in this study might help address the issue of whose perceptions in adolescence best predict future self-perceptions of outcomes related to quality of life.

5) Differences may emerge between groups later in adulthood. The lack of

differences in many areas may be due to the fact that the young men in both groups were still in a state of transition and it is too early in the process of their development to capture long-lasting differences in outcome and quality of life. It is possible that it is not until the period of transition into adulthood is over that differences will truly emerge.

Summary

In conclusion, it is apparent that Asperger Syndrome has an impact on a person's quality of life. The characteristics associated with variations in quality of life provide insight into the client's life. The physical and the social domain should be addressed in rehabilitation intervention to directly enhance their quality of life thus allowing these individuals to successfully participate in meaningful and age appropriate occupations. These findings underline the need to consider the impact on all the areas of their lives as the reduction of the negative impacts of Asperger Syndrome on quality of life, whether physical or social, can not be accomplished only by medical or psychosocial services alone but requires intervention from a more holistic model of practice which includes all aspects of one's life.

Other variables such as social support, living arrangements, leisure activities, and education were investigated but did not appear to be different compared to those matched on age and gender. These findings provide parents, educators and others dealing with those with Asperger Syndrome with some hope as in many areas, these persons are not doing all that differently when compared to those matched on age and gender. This finding infuses some hope for the prognosis of certain individuals with Asperger Syndrome.

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APPENDIX A

Introductory letter

Telephone script

UNIVERSITY OF ALBERTA

INTRODUCTORY LETTER

Dear_______________,

Six years ago, you participated in a study of adolescents conducted by Cyndie Koning. In that study, you watched a video and guessed what the students in the video were feeling. Now, a graduate student at the University of Alberta would like to see how your life circumstances and quality of life has changed over the last six years. This letter is an invitation for you to participate in her study. This information may help us provide appropriate services to improve the quality of life of young adults in general.

If you decide to participate, Marieke Coussens would visit you once in your home for a maximum of 2 hours. This would happen this summer. First, she will interview you for about half an hour. You will be asked about employment, education, and living arrangements, among other items. Then she will give you some questionnaires. They cover your feelings about health and life in general. We will also need some personal information such as your date of birth. You may refuse to answer any question. All information will be confidential and no information that identifies you will be included in any report on the study.

I will be calling you in the next few days to ask if you are willing to have your address and phone number given to the graduate student. We would also like to use the information from six years ago. If you have any questions, please call me at 492-6104. Otherwise, I look forward to talking to you.

Thank you for considering this request.

Sincerely,

Cyndie Koning, MSc. OT (C)
Sessional lecturer
Department of Occupational Therapy, Rehabilitation Medicine
University of Alberta

UNIVERSITY OF ALBERTA

Telephone script

After confirming that the person is one of the previous study participants (by name)

Cyndie:	Hi. My name is Cyndie Koning and I am contacting you to see if you received my letter. Is this an OK time for you?
Possible Participant:	1) no, ask about a more convenient time and call back then. 2) Yes, proceed to next question
Cyndie:	Did you get my letter?
Possible participant:	1) no, check whether the address it was mailed to is correct. Cyndie will then briefly explain what is said in the introductory letter and tell the possible participant that another copy will be sent. 2) Yes, proceed to next question
Cyndie:	As I mentioned in the letter, 6 years ago you participated in a study of teens. In that study, you watched a video. You were asked to try and figure out what the people on the video were feeling. You and one of your parents also had to fill in some forms. Do you remember this study?
Possible participant:	1) no, provide more details 2) Yes, proceed to next question
Cyndie:	We'd like to go back and look at the information from that study. Is that OK with you?
Possible participant:	1) yes, continue to next question 2) No. (Thank them for their time)
Cyndie:	We also want to learn about how you are doing now and about your quality of life. In order to look at this we would like your permission to have a graduate student contact you to participate in this new study. Her name is Marieke Coussens. Would it be OK for her to contact you in mid June about participating in the new study?

Possible participant: 1) yes, confirm contact information
2) No (Thank them for their time)

Cyndie: Thanks for your help. We really appreciate this. You can call me anytime with questions. My number is 492-6104.

APPENDIX B

Introductory Letter

Information Letter

Consent form

UNIVERSITY OF ALBERTA

Introductory Letter

Dear_________________,

My name is Marieke Coussens. I am a graduate student in occupational therapy. I am really interested in learning more about quality of life of young adults. Cyndie Koning called you and determined that you were willing to be contacted by me.

I would like to invite you to participate in my study. Please read the attached letter. I will be calling you in the next couple of days to answer any questions and to see if you are interested in helping us out with the study.

Thank you very much

Marieke Coussens
Graduate Student, Department of Occupational Therapy
Faculty of Graduate Studies and Research - Rehabilitation Medicine
The University of Alberta

UNIVERSITY OF ALBERTA

INFORMATION LETTER

A study of quality of life in young adults

Investigator: M. Coussens, OT
Rehabilitation Medicine
University of Alberta
Tel. (780) 431-8411

Supervisors: J. Magill-Evans, PhD, OT
Professor, Dept. of OT
University of Alberta
Tel. (780) 492-0402

Cyndie Koning, MSc. OT Lecturer,
Dept. of OT
University of Alberta
Tel. (780) 492-6104

Purpose?

This study looks at what young adults think about their quality of life and social support. We are also interested in how you are doing at your work, school, and home as well as what you like to do for fun.

What will you be asked to do?

If you agree to participate, it will take a maximum of 2 hours. Two questionnaires will be mailed to you. In the first questionnaire, you will rate your quality of life. The second questionnaire examines your support network. Marieke Coussens will then schedule an interview with you. She will ask questions about where you live and with whom, if you are student, your age and other similar questions. The interview will take about 30 to 45 minutes. This information will be tape-recorded so that we can remember what you said. The interview will be done at a place that suits you. After the interview, Marieke will ask for the completed questionnaires.

Benefits and Risks?

Although this study will not help you right now, the information will facilitate the development and evaluation of programs for young adults. This will help professionals better understand quality of life as defined by young adults. A potential risk is that the questions may be upsetting. If you are upset and you would like to speak with a professional, we will refer you to available community resources.

What will happen to the information?

Your participation is voluntary. You may refuse to answer any questions. You may refuse to participate or you may withdraw at any time without any consequences. All information will be private, except when professional codes of ethics or the law requires reporting. The information will be kept for 7 years after the study. It will be locked in a filing cabinet. Your name and other identifying information will not be attached to the information you gave. Your name will never be used in any presentations or publications.

The information gathered for this study may be looked at again in the future. If so, the ethics board will first review the study to ensure the information is used ethically.

Do you have any questions?

You may contact Marieke Coussens at 431-8411 if you have any study-related questions. You may also call Cyndie at 492-6104 or Joyce at 492-0402.

If you have any concerns about any aspect of the study, you may contact the Associate Dean for Graduate Studies, Paul Hagler at 492-9674.

Thank you very much for your help!

UNIVERSITY OF ALBERTA

CONSENT FROM

Title of project: A follow-up study of quality of life in young adults

Investigator: Marieke Coussens, OT, Masters Candidate,
Department of Occupational Therapy, University of Alberta.
(780) 431-8411 or coussens@ualberta.ca

Supervisors: Joyce Magill-Evans, PhD.,
Department of Occupational Therapy, University of Alberta
2-30 Corbett Hall, Edmonton, Alberta, T6G 2G4,
(780) 492-0402 or Joyce.Magill-Evans@ualberta.ca

Cyndie Koning, MSc.,
Department of Occupational Therapy, University of Alberta
2-10 Corbett Hall, Edmonton, Alberta, T6G 2G4,
(780) 492- 6104 or ckoning@ualberta.ca

Do you understand that you have been asked to be in a research study?
YES NO

Have you read and received a copy of the attached information sheet?
YES NO

Do you understand the benefits and risks involved in taking part in this research study?
YES NO

Have you had an opportunity to ask questions and discuss the study?
YES NO

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.
YES NO

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?
YES NO

This study was explained to me by: ______________________

Date: ______________________

I agree to take part in this study: ___________________ ________________

Signature Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Researcher: ___________________ Printed Name: ___________________

Witness: ______________________ Printed Name: ___________________

APPENDIX C

The World Health Organization Quality of Life

(WHOQOL-BREF)

WORLD HEALTH ORGANISATION
QUALITY OF LIFE

WHOQOL-BREF

About you

Before you begin we would like to ask you to answer a few general questions about yourself by circling the correct answer or by filling in the space provided.

What is your birthday? (Day, month year)____________________

Are you currently ill? YES NO

If something is wrong with your health what do you think it is? ____________

Instructions

This assessment asks how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

Example:	**Not at all**	**Slightly**	**Moderately**	**Very**	**Completely**
Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle the number 4 if in the last two weeks you got a great deal of support from others

	Not at all	**Slightly**	**Moderately**	**Very**	**Completely**
Do you get the kind of support from others that you need?	1	2	3	4	5

But if you did not get any of the support from others that you needed in the last two weeks you would circle 1.

Thank you for your help.

Now turn to the **back** of this page >

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
1. How would you rate your quality of life?	1	2	3	4	5

	Very dissatisfied	**Fairly dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
2. How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the **last two weeks.**

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5. How much do you enjoy life?	1	2	3	4	5
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
7. How well are you able to concentrate?	1	2	3	4	5
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how **completely** you experience or were able to do certain things in the last two weeks.

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
10. Do you have enough energy for every day life?	1	2	3	4	5
11. Are you able to accept your bodily appearance?	1	2	3	4	5
12. Have you enough money to meet your needs?	1	2	3	4	5
13. How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

	Very poor	**Poor**	**Neither poor nor good**	**Good**	**Very good**
15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	**Fairly dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
16.How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with yourself?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5

21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

	Never	**Seldom**	**Quite often**	**Very often**	**Always**
15. How often do you have negative feelings such as a blue mood, despair, anxiety, and depression?	1	2	3	4	5

Did someone help you fill out this form? ______________________________
How long did it take to fill this form out? ______________________________
Do you have any comments about the assessment? ______________________

THANK YOU FOR YOUR HELP.

Steps for Checking and cleaning data and computing domain scores (WHOQOL)

Steps	SPSS syntax d for carrying out data checking, cleaning and computing total scores
1. Check all 26 items from assessment have a range of 1-15	Recode Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS). (This recodes all data out with the range 1-5 system missing
2. Reverse 3 negatively phrased items	RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1) (This transforms negatively framed questions to positively framed questions.
3. Compute domain scores	**COMPUTE DOM 1**= MEAN.6 (Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4 **COMPUTE DOM 2**=MEAN.5 (Q5,Q6,Q7,Q11,Q19,Q26)*4. **COMPUTE DOM 3**=MEAN.2 (Q20,Q21,Q22)*4 **COMPUTE DOM 4**=MEAN.6 (Q8,Q9, Q12, Q13, Q14, Q23, Q24, Q25)*4 (These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domains scores to be calculated
4. Delete cases with > 20 % missing data	COUNT TOTAL=Q1 to Q26 (1 thru(5). (This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-100 items with the value 1-5 that have been endorsed by each subject. The 'Q1 to Q26' means that consecutive columns from'Q1' the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment. FILTER OFF USE ALL SELECT IF (TOTAL > or = 21) EXECUTE (This second command selects only those cases where 'total', the total number of times completed, is greater or equal to 80%. It deletes the remaining cases from the data set).
5. Check domain scores	DESCRIPTIVES VARIABLES=DOM1 DOM2 DOM3 DOM4/STATISTICS=MEAN STDDEV MIN MAX. (Running descriptives should display values of all domain scores within the range 1-20).
6. Save data set	=save data set with a new file name so that the original remains intact.

APPENDIX D

Perceived Support Network Inventory

(PSNI)

Perceived Support Network Inventory (PSNI)

The support we receive from family, friends, professionals, and others during times of stress plays an important role in our reaction to that stress. The interaction that we have with supportive individuals helps us feel better after flunking an exam, losing a job, or experiencing conflict with someone. This questionnaire gathers information about your perceptions and experiences with your support network during stressful events.

SUPPORT NETWORK LIST

Write the first name and last initial of all the people you would go to if you needed support or help during a stressful time. Check the column that describes your relationship with each person. You do not have to fill out this list in any order. You do not have to use all the spaces available.

First name, last initial	**Spouse/ Partner**	**Family Member**	**Friend**	**Co-worker**	**Professional**	**Religious Leader**	**Self-help group member**

HELPING BEHAVIOURS

Support from people during stressful events falls into five categories:

a) Emotional support: someone listening to your private thoughts and feelings and/or giving you physical affection.
b) Material aid support: someone lending you money or the use of some valuable object like a car.
c) Advice and information: someone suggesting what to do or where to get needed information
d) Physical assistance: someone helping with jobs around the house, errands, or favours you might need.

e) Social participation: someone offering you the opportunity to engage in pleasant social activities.

f)

SUPPORT NETWORK INFORMATION

On the following pages are questions about the people you listed on the Support Network List. Please write the first name and last initial of the first person you listed and answer the questions about him/her. Then write the first name and last initial of the second person you listed and answer the questions about him/ her. Go through your entire Support Network List. The questions for each person take less than a minute to answer, so the following pages will not take long.

Person number 1

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support or help	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 2

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 3

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7

I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 4

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some- times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1 2 3 4 5 6 7
Almost Never Sometimes Usually Almost Always

Generally speaking, I have serious conflicts with this person.

7 6 5 4 3 2 1
Almost Never Sometimes Usually Almost Always

Person number 5

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1 2 3 4 5 6 7
Almost Never Sometimes Usually Almost Always

Generally speaking, I have serious conflicts with this person.

7 6 5 4 3 2 1
Almost Never Sometimes Usually Almost Always

Person number 6

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 7

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 8

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 9

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 10

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 11

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7

I am satisfied with this person's support 1 2 3 4 5 6 7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Person number 12

First name, last initial____

Rate the extent to which you agree with the following statements by circling the appropriate numbers.

During times of stress:	Almost never		Some-times		Usually		Almost always
I seek this person out for support or help	1	2	3	4	5	6	7
This person provides me with support or help when I ask	1	2	3	4	5	6	7
I am satisfied with this person's support	1	2	3	4	5	6	7

Place a check next to the categories of support you might expect to receive from this person during times of stress:

_____ a) Emotional Support
_____ b) Material Aid Support
_____ c) Advice and Information
_____ d) Physical Assistance
_____ e) Social Participation

This person receives support from me during times of stress for him/her.

1	2	3	4	5	6	7
Almost Never		Sometimes		Usually		Almost Always

Generally speaking, I have serious conflicts with this person.

7	6	5	4	3	2	1
Almost Never		Sometimes		Usually		Almost Always

Thank you very much!

APPENDIX E

Semi-Structured Interview

APPENDIX E

Semi-Structured Interview

ID number: ________________________ Address: ____________________

Date of Interview: ___________________ ____________________

Place of interview: __________________ ____________________

Phone: ___________________________ Email: ____________________

Hi *(name of participant).* **How are you?** (*Answer of participant*)? **Is it okay to start the interview?** (*Answer of participant*). **As you already know, my name is Marieke and I am going to ask you some questions about school and work, where you live right now and what you do for fun. I am also going to ask you some questions about your social relationships. Is that okay with you?** (*Answer of participant*) **Do you have any questions so far?** (*Answer of participant*) **If you have any questions during the interview, just stop me and I will try to answer them for you** (*answer of participant*)**. I am going to start the tape-recorder now so I can remember your answers. Is that ok for you?** *(Answer participant).* **Is everything clear?** (*Answer of participant*) **Okay, so let's start.**

LEVEL OF INDEPENDENCE

Question 1: **Are you currently in school or are you going to school within the next few months?**

YES: Probes:

1. **Where do you go to school?** ________________________________
2. **What are you taking?** ________________________________
3. **What year are you in?** ________________________________
4. **When do you plan to graduate?** ________________________________
5. **So, that means that you have about ___ years of full time education?**

6. **Do you work as well?** If no, go to question # 2, probe # 4.

If yes, **are you a full time or a part time student?** ___

7. **When did you graduate from High school?** ____________________________

8. **Which courses did you take in high school?** ____________________________

NO: Probes: **1. Do you plan to go back to school?** __________________

2. Where did you go to school? ______________________

3. Did you get a high school diploma? __________________

If YES: **1. Did you take anything after high school?** _______

2. Did you take anything else? __________________

IF NO: **1. What grade did you complete?** ________________

2. What courses did you take? __________________

3. What were you taking? ______________________

4. What year did you quit school? ________________

5. When do you plan to graduate? ________________

6. How many years of full time education in total do you think you currently have? _________________

Question 2: **Are you working right now?**

YES: Probes:

1. What do you do for work? ______________________________________

2. Who do you work with? Is it mostly you alone or with other people? ______

3. How did you get this job? ______________________________________

4. Have you had any other jobs in the last couple of years? ________________

YES: Probes:

1. How many jobs did you have before this one? ___________

2. What kind of jobs were they? ________________________

3. Could you tell me why you've changed jobs?

___ (1) temporary job

___ (2) earn more money

___ (3) don't like it

___ (4) too stressful

___ (5) other___________________________

NO: go to probe # 1: **Have you ever had a paid job before?**

5. How many hours do you work per week on average? ___________________

6. How much do you make an hour? ___________________________________

Probes: **So___ hours per week and _______ $ per hour, is that right?**

Probes when reluctant to provide information: **Do you earn more than_______** (18,371 a year or 1530 $ a month or 382 a week) **or less than** ______ (18,371 a year or 1530 $ a month or 382 a week)?

NO: Probes: **1. Have you ever had a paid job before?** _____________________

YES: Probes: **1. How long ago did you have a paid job?** _______

2. What did you do for work? _________________

3. Who did you worked with? Was it mostly you alone or with other people?__________________

4. How long have you been working at this job? __

5. Have you had any other jobs in the last couple of years? ___________________________________

6. How much do you receive on average per month? __________________________________

Probes when reluctant to provide information: **Do you receive more than______** (18,371 a year or 1530 $ a month or 382 a week) **or less than** __________ (18,371 a year or 1530 $ a month or 382 a week)?

NO: continue with probe # 1

1. So, what do you do for money? Do you have any other source of income? ________________________________

2. Tell me what you know about that program? __________

3. How much do you receive on average per month? ______

Probes when reluctant to provide information: **Do you receive more than______** (18,371 a year or 1530 $ a month or 382 a week) **or less than __________** (18,371 a year or 1530 $ a month or 382 a week)?

Question 3: Now, lets' talk about your home. Who do you live with? Tell me about where you live.

_____ (1) by yourself

Probes: **So do you have your own place? ___________________________**

_____ (2) with your parents/relatives

Probes: **1. How does this work out for you? ___________________________**

2. How long do you think you will be living at home? __________

3. Do you pay rent? ___________________________________

4. Who else do you live with/ brothers/ sisters. Do they pay rent as well? ____

5. Do you have to do any household choirs? __________________

_____ (3) with your partner

Probes: **Do you have your own place? ___________________________**

_____ (4) with friends

Probes: **Do you share a house/ apartment? _______________________**

_____ (5) in a residence

Probes: **1. What kind of residence? _______________________________**

2. Does your residence provide you with any kind of services such as meals? YES: _______________________________

NO: _______________________________

Question 4: How do you get around town?

_____ (1) drive own vehicle

When did you get your driving license? ___________________________

_____ (2) drive other vehicle

Can you use your parents'/friends car? ______________________________

When did you get your driving license? ______________________________

_____ (3) public transport

Do you have a driving license? YES: **Since when?** ____________________

NO: **Are you planning to get your driving license in the near future?**_________

_____ (4) other: _____________

ENVIRONMENT: Leisure Activities

Question 5: Now, I'm going to ask you some questions about what you like to do for fun.

1. **What are your three favourite hobbies or activities?**
   (1) ____
   (2) ____
   (3) ____
2. **How many times a week do you do that? (activity # 1, 2, 3)?**
   (1) ____
   (2) ____
   (3) ____
3. **Who do you do these activities with?** ____________________________________
4. **Are you in any kind of volunteer groups or organizations?**

YES: Probes: 1. **What kind of organizations/volunteer groups are you in?** ______
2. How often did you participate? ____________________________

NO: **1. Have you ever been in an organization?**
YES: Probes: 1. **What kind of organizations/volunteer groups were you in?** ____________________________
2. How often do you participate? ______________

We are almost finished with this interview *(name of participant).* **Just a few more questions and we can wrap up. Do you have any questions so far?** *(Answer participant)*

SOCIAL RELATIONSHIPS: Friends and Dating

Question 6: **Now I'm going to ask you some questions about your social relationships.**

1. Out of the top of your head, could you name who are really your close friends?

____

2. How many close friends do you have, not including your brothers and sisters?

____ (1) none

____ (2) one

____ (3) two or three

____ (4) four or more

How long have you known them? ______________________________

How did you meet them? ______________________________

2. How often did you see or did you talk to these people in the last month?_______

Probe for more specific information, only if not already mentioned by the participant:

What do you like to do with these friends outside of regular school or work?

____

Probe when participant answers 'none' to question 6 (#1): **Would you like to tell me more about it?**______________________________

3. Are you currently in a relationship with someone?

YES: Probes:

1. Tell me about how you met______________________________

2. How long have you been together? ______________________________

3. Is this your first relationship? ______________________________

YES: ______________________________

NO: continue with (*)

NO: Probes: **1. Have you been dating before?**

NO: ______________________________

(*) YES: Probes: **1. Tell me about those relationships/ what were they like?**______________________________

2. How many relationships did you have in the past?

We have talked about a lot of things. Is there anything else that you'd like to add that we haven't covered in this interview? ___________________________________

Well (*name of participant*), that's all I am going to ask you.

Do you have any other comments or questions about this interview?

YES: _______ NO: ____________

Did you receive the 2 questionnaires that I sent you?

YES: _______ NO: ____________

Do you have any questions about these questionnaires?

YES: _______ NO: ____________

Are you interested in receiving a report of the results of this study?

YES: _______ NO: ____________

Where would you like the results to be sent?

Results send to: _____________________
____
____

My phone number and email address are on your copy of the consent form if you come up with things you would like to ask related to this study. I really appreciate you taking some time to take part in this interview. Okay, then *(name participant)* thanks again and have a nice day.

Coding Scheme for Interview data

Quality of life domain	Aspects of domain	Variables	Descriptive statistics
Level of Independence	Education	# of years of full time education	Mean and SD
		Full-time / part-time student	%
		Kind of education: high school college, university	%
Level of Independence	Employment	Currently employed, not employed, never had a paid job	%
		Kind of occupation: will be categorized	%
		# of hours worked per week	Mean and SD
		# of jobs held in total so far	Mean and SD
		Monthly average income	Mean and SD
		Duration employment	Mean and SD
Level of Independence	Living Arrangements	With parents, partner, by yourself, residence and friends	%
Level of Independence	Mobility	Getting around: own car, drive other car, public transport	%
		Driving license or not	%
Environment	Leisure	Kind of activities: will be categorized into more solitary act. (i.e., TV, computer) and social act. (Going out with friends)	%
		# of hours spent per week	Mean and SD
		Participation, no participation, never belonged to one	%

Environment	Volunteer groups/ organizations	# of groups/ organizations belong to	Mean and SD
		Kind of organizations: will be categorized later	%
Social Relationship	Friends	# of close friends	Mean and SD
		# of things done with close friends	Mean and SD
	Relationships	Currently in relationship, not in relationship, never been in relationship	%

APPENDIX G

The Support Network Edmonton's Distress and information center

Address: 301-1146 Jasper Avenue
Edmonton AB T5K 0M1
Phone: (780) 482-0198
Fax: (780) 488-1495
Email: counselling@thesupportnetwork.com
Website: www.thesupportnetwork.com
Hours: Monday and Tuesday from 1:00 p.m. to 8:00 p.m.
Wednesday from 9:00 am - 4:00 p.m.
Thursday; call to confirm hours and wait times
Access: telephone, walk-in
Fees: None
Severs:
- Community members who desire immediate counselling with an accessible, no-cost, walk-in counselling services.
- Uses solution-focused approach by qualified professional community therapists to families, couples, and individuals who are troubled by life or relational issues.

Distress Line: The Support Network

Phone: (780) 482-4357
Toll Free: 1-800-232-7288
West View and Aspen Health Authorities, Drayton Valley, High Prairie
Website: www.thesupportnetwork.com
Hours: 24 hr
Services:
- Provides confidential, anonymous 24 hr telephone line for people in crisis or experiencing difficulty in their lives.
- Provides information and referral to community services.

Crisis Intervention and Stabilization

Address: 4800 55 Avenue
Stoney Plain AB T7Z 1P9
Contact: Meryl Murray/ Liz Gawenus
Phone: (780) 963-6151
Ext. 148; (780) 963-7192
Email: Connie.Pollard@westviewRHA.ab.ca
Hours: Monday trough Friday from 8:00 am to 4:00 p.m.
Access: Telephone, appointment recommended
Serves: Anyone experiencing psychiatric/ emotional crisis in Spruce Grove, Stoney Plain, Devon and Parkland County
Services: Provides individuals who are experiencing a psychiatric / emotional crisis with a continuum of community services/ resources at a time when they are unable to provide for themselves.